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DIANE JEAN BISSMIRE BA Hons.

**HOW PROMOTING ARE PROFESSIONAL STAFF WORKING
WITHIN COMMUNITY LEARNING DISABILITY TEAMS OF
CLIENTS HAVING SEXUAL RELATIONSHIPS, AND WHAT
ARE THE FACTORS INVOLVED IN THIS?**

**A thesis submitted in partial fulfilment of the requirements of the
Open University for the degree of Doctor of Clinical Psychology.**

JULY 1998

**SALOMONS
CANTERBURY CHRIST CHURCH COLLEGE**

17,000 words.

DATE OF AWARD: 16 SEPTEMBER 1998

DECLARATION

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed DMB (candidate)

Date 15.7.1998

STATEMENT 1

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

Signed DMB (candidate)

Date 15.7.1998

Signed Vicky Turk (supervisor)

Date 8/7/98

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Lastly but certainly not least, I would like to thank Pete who as usual has provided invaluable support at a stressful time.



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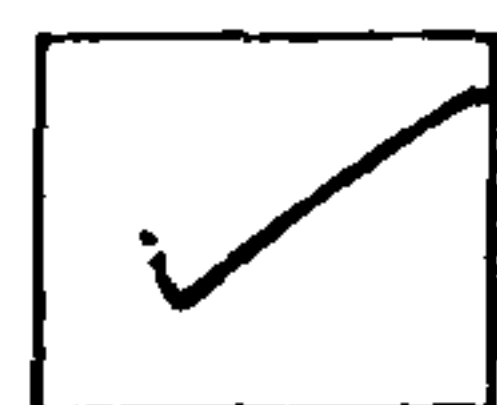
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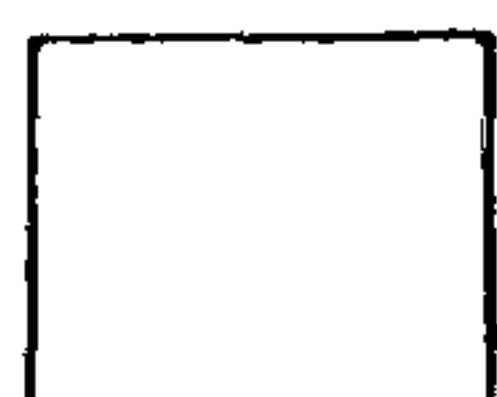
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Abstract:

It was hypothesised that previous experience of working with issues concerning sexuality and clients with learning disabilities, knowledge, and overall experience of working with the client group would influence decisions professional staff made concerning sexuality and risk. A questionnaire was devised comprising the following four sections: 1. Demographic details. 2. Changes in levels of promotion / protection of clients since qualifying in a profession. 3. Knowledge questions concerning issues of sexuality. 4. Scenario based questions relating to sexuality and relationship issues.

The questionnaires were completed by 78 professional members of community learning disability teams. A significant positive correlation was found between knowledge scores and scenario scores, indicating that the more knowledgeable the individual is the more protective they are of clients. Additionally, a significant positive correlation was found between the amount of experience dealing specifically with sexual relationships and knowledge scores.

A significant negative correlation was found between the amount of experience gained in dealing with clients experiencing heterosexual relationships and the score gained in the scenario concerning that issue. A significant negative correlation was also found between the amount of experience gained in dealing with sexual health issues and the score in the relevant scenario. This indicates that the more experience the participant has in dealing with heterosexual relationships and issues around sexually transmitted diseases, the more promoting they are when assessing the risks in a related scenario.

A polarisation of views was noted in the scoring of some of the scenarios. The clinical implications are discussed as well as possible improvements in questionnaire design. Suggestions are made concerning directions for future research.

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1. Introduction:

With the move towards care in the community, attention has been focused on aspects of service users rights and service responsibility to reduce risk to the general public. This has been seen particularly in the area of mental health and has led to initiatives such as the introduction of the Care Programme Approach (NHS Executive, 1996). Sexuality has been another area of concern with more awareness of abuse and offending issues and more heightened concern over HIV and the spread of infection. Changes to legislation and recent press and media coverage have led to an increase in society's concern about sex offenders in the community. Despite these changes in policy and practice there is little research on how professionals make judgements about risk, particularly risk concerning sexuality and people with learning disabilities.

This introduction will begin by describing the movement towards community living for people with learning disabilities and the philosophy behind this movement. These ideas are the basis for setting the scene for current thinking around issues of choice and autonomy for clients living in the community and the staff that work with them. Issues concerning sexuality for people with learning disabilities will then be discussed. These will include sexual relationships and possible abuse, staff and carer attitudes, and an exploration of the role of staff in making decisions based on assessing levels of risk for clients. This section will end with an outline of the research questions and hypotheses which form the basis of this study.

1.1. The move towards community living for people with learning disabilities.

Within the last thirty years or more there has been increasing criticism of the traditional long-stay institutional form of care provided for many people with learning disabilities. These institutions were criticised for many reasons which included their large size, the separation of residents from community life and segregation from the outside world, and

the ‘degrading’ and sometimes ‘abusive patterns of relationship’ that can characterise an institutional culture (Emerson, Felce, McGill and Mansell, 1994). Subsequently, in recent years the emphasis in long-term service provision for people with learning disabilities has moved towards a ‘community’ based approach, in which services are smaller, located within ordinary communities with higher levels of staff-client ratios and focused on social care, enabling and support.

Between the years 1980 and 1993 the capacity of mental handicap hospitals in the UK was reduced by over 26,000 places and resulted in many thousands of people with learning disabilities moving from hospitals into the community (Emerson and Hatton, 1994). The implementation of the NHS and Community Care Act (1990) has resulted in major changes in the way that services for people with learning disabilities are organised. Other important factors in this reorganisation are the separating of commissioning or purchasing from service provision, the increased role of Local Authorities and the independent sector, and the introduction of new procedures for assessment and care management and for monitoring services (Emerson and Hatton, 1994).

A model of living that involved ordinary housing was proposed by the King’s Fund paper ‘An Ordinary Life’ (King’s Fund, 1980). This paper is based on three key principles: that people with learning disabilities have the same ‘human value’ and therefore the same human rights as anyone else; living like other people in the community is both a need and a right; that services need to recognise the individuality of people with learning disabilities. The right to live like others in the community includes the opportunity to form different relationships, ranging from casually supportive relationships, to closer friendships and ‘mutually supportive relationships’ between two people of opposite sexes or the same sex.

It is stated that a comprehensive, community-based residential service should provide a range of places for people to live in, and a ‘real’ choice should be available for the individual among the different sorts of home-life that would be ‘recognised as such’ by

the community. Emerson and Hatton (1994), in their review of the literature which had been published since 1980 concerning the effects of the move from hospital to community on the lives of people with learning disabilities (in the UK) identify four categories of residential accommodation. These are: hospitals, hostels or 'units,' staffed houses providing 24 hour staff support in 'ordinary' housing and independent living or family placement schemes.

1.2. Normalisation and the 'five accomplishments.'

Instrumental in the changes in the way that service provision for people with learning disabilities have been conceptualised were the theories of Normalisation, or Social Role Valorisation as it later evolved into (Wolfensburger 1972, 1983). The 'highest goal' of this theory is described as enhancing, establishing or defending the social roles of a person or group, 'via the enhancement of people's social images and personal competencies' (Wolfensberger, 1983). Within traditional institutions people with learning disabilities were largely unable to adopt valued social roles, a situation that was in opposition to the values of Normalisation.

Similarly, Vanier (1986, cited by Waitman and Reynolds 1992) offers a model that attempts to empower rather than devalue the individual. It offers a learning approach through acceptance of people for their 'richness and variety,' rather than a circle of 'deprivation and rejection' which reinforces the negative values previously attached to people with learning disabilities. Within his model the negative results of society's behaviour towards people with learning disabilities are described (see Appendix 1). These include lack of experience and opportunity so that the individual becomes overprotected, and a lack of opportunity to develop relationships with others. These negative experiences are described as the 'wounds' of people with disabilities.

A 'negative learning circle' occurs as a result of these life experiences. Prejudiced beliefs about 'slow learners' leads to low expectations. Opportunities to learn are not given because of this, which results in a lack of experience or negative experience and finally leads to more delay and learning deprivation. By removing the 'wounds' described earlier a 'positive learning circle' is possible. The individual is valued and there are high expectations of them. This creates a wide range of learning opportunities, leading to an increase in positive experience whereby the person learns and develops (Waitman and Reynolds, 1992).

In their approach to providing good quality services, Blunden and Allen (1987) start with the premise that people with learning disabilities have the same human value as anyone else; have a right and a need to live like others in the community; and need services that will recognise their individuality.

These values and concepts have been operationalised by O'Brien (1987) into his 'five accomplishments' which are often cited now as aims of service provision when assessing quality of life issues for people with learning disabilities (e.g. Department of Health report 1993). These accomplishments are summarised as, Community presence, Choice, Competence, Respect, and Community participation.

Community presence refers to the sharing of the 'ordinary' places that define community life as opposed to segregated facilities and 'special activities.' *Choice* is the experience the person has of being autonomous in the decisions they make about their life. This may vary from everyday matters such as what to wear, to more life changing events, such as what sort of work to do. *Competence* refers to the opportunity to carry out meaningful activities with whatever level of assistance is needed. *Community participation* is the experience of having a network of personal relationships including close friends, and *Respect* means having a valued place amongst these networks and a valued role in community life (O'Brien 1987).

Translating the five principles into the area of people's sexuality has led to many challenges as it forces a basic acknowledgement of the person's rights as an adult. Craft (1983) summarises the meaning of normalisation theories as specifically regards the sexuality of people with learning disabilities. The 'rights' she identified were:

1. The right to receive training in social-sexual behaviour that will lead to more social contact with people in the community.
2. The right to all the knowledge about sexuality that they can comprehend.
3. The right to enjoy love and to be loved, including sexual fulfilment.
4. The right for the opportunity to express sexual impulses in the same form that are socially acceptable for others.
5. The right to birth control services, specialised to meet their needs.
6. The right to marry.
7. The right to have a voice in whether or not they should have children.
8. The right for supportive services which involve those rights as they are needed and feasible. (pg 2).

It is important to be aware though that despite the progress made in recent years most people with learning disabilities are still unable to choose where they live, who they live with or which agency supports them 'let alone who they have sex with' (Cambridge, 1996). This highlights the difficulties inherent in promoting people's sexual rights. Often issues of sexuality have been seen as the 'cutting edge' of normalisation.

1.3 Sexuality and People with Learning Disabilities.

1.3.1. Sexuality and the Law.

People with learning disabilities can be affected by laws on sexual behaviour in two ways (Gunn, 1996). Firstly, there are laws which make reference specifically to people with learning disabilities. Secondly there are laws which make no specific reference to this population and in these cases all people with learning disabilities will be treated in law the same as the rest of the population.

An example of the former is in the case of sexual intercourse and rape. If the woman with learning disabilities cannot actually consent, a man having sex with her is committing the offence of rape because the woman can provide no consent. It is the meaning of 'consent' which is important though and this can be interpreted at different levels. If a 'low standard' of interpretation is adopted, which requires simply an understanding of penile penetration and that it is a sexual act, then many women with learning disabilities will be able to provide consent. However, if a 'higher standard' is used that requires an awareness of the significance of sexual intercourse and its implications for the woman, fewer women with learning disabilities would be able to consent.

The advantage of the former approach may be that more women with learning disabilities can enjoy sexual relationships whereas the advantage of the latter approach can be that it protects more women from exploitation and abuse. This is just one example of possible areas of uncertainty and highlights the ethical and moral decisions that staff may have to make when dealing with sexuality issues.

1.3.2. Attitudes Towards Sexuality and People with Learning Disabilities.

Craft (1983) writes that there has been a change in emphasis concerning the sexuality of people with learning disabilities. The early thinking in this area is described as concentrating primarily on the negative consequences of sexual activity and is focused on the 'good of society.' The fear that people with learning disabilities would themselves have children with disabilities fuelled the earlier thinking (MacKenzie and MacKenzie, 1977) and led to laws in the USA allowing sterilisation and forbidding marriage. Additionally the prevailing view of sex education appeared to be that the less a person with a learning disability knew about sex 'the better' (Pitcaethly and Chapman, 1985). Later authors are described as writing mainly in the context of the 'positive' results of aiding people with learning disabilities 'to live sexually satisfying lives'.

The attitudes of care staff towards the sexual behaviour of clients with a learning disability have at times reflected the wider views of society. Studies carried out in the 1970s and early 1980s indicated that attitudes towards the sexual behaviour of people with learning disabilities were generally negative (Murray and Minnes, 1994). An example of this are the findings of Mitchell, Doctor and Butler (1978). These indicated that 31 per cent of the care staff working in three residential facilities felt that no sexual behaviour was acceptable, including simple physical contact. It was suggested therefore, that sex-education programmes for residents could be met with resistance by a 'substantial percentage' of the staff. Similarly, Haavik and Menninger (1981) found that amongst care staff, only limited expressions of sexuality such as kissing or holding hands were tolerated.

A more recent study looking at staff attitudes by Murray and Minnes (1994), indicated that in contrast to earlier findings, staff attitudes towards the sexuality of their clients were moderately liberal. This finding was replicated by a later study in which staff attitudes towards client sexuality were described as generally being 'highly liberal' (Murray and McDonald, 1995). It was also found that non-direct care staff had

marginally more positive attitudes towards people with learning disabilities and AIDS than the direct care staff. Interestingly, Murray and Minnes also made a comparison between attitudes towards sexuality of professional staff and direct care staff. Professional staff were found to have less 'conservative' attitudes towards the sexuality of the client group than direct care staff.

These findings, it is suggested emphasise the need to assess staff attitudes prior to the implementation of sex education programs as those staff with conservative attitudes could 'jeopardise the success of such programs'. It is stated that training sessions to facilitate greater tolerance of 'non-stereotypical views' of the sexuality of clients could be useful, and would include greater support for client choice of sexual expression.

Kempton (1983) has previously emphasised the view that for carers and / or professionals the role of significant adult to others creates an 'additional responsibility,' which is to be aware of the impact that knowledge, attitudes and values can have on the 'environmental, experiential, or formal education' of those influenced. Four stages of attitudes relevant to the sexuality and sexual expressions of people with learning disabilities are described by Kempton and Caparulo (1983). These are: to 'eliminate' the person's sexuality; to 'tolerate' their sexuality; to 'accept' their sexuality and to 'cultivate' their sexuality. The latter is further described as an attitude by which people with learning disabilities can be encouraged and helped to 'enrich their lives' through sexual expression. The authors though advocate the approach of acceptance as it was felt that society was not yet ready for a more 'progressive' policy.

It has been indicated by several studies that adults with learning disabilities have a negative view towards their own sexuality (e.g. Brantlinger 1985, Pueschel and Scola, 1988). This is explained in terms of the 'symbolic' environment in which sexuality is defined for the person by their carers (Heyman and Huckle, 1995). Parents are described as often believing that the individual does not have sexual needs, cannot understand cultural rules about acceptable sexual behaviour and cope with sexual relationships and

would not be accepted in a sexual relationship by the community. These views result historically in many parents being reluctant for their children to have sex education (Squire, 1989).

Brown and Turk (1993) point out that parents have usually been more cautious and protective about advocating sexual rights than paid workers as they are anxious that sexual expression may lead to rejection or exploitation and realise that stating people's rights, in isolation from responsibilities is both 'naive and simplistic.' The parents may subsequently be left to cope with the longer term consequences of sexual relationships, such as marriage and parenthood or the breakdown of a relationship, whilst professional support is usually short-term and intermittent due to changes in personnel, priority shifts and lack of resources (Heyman and Huckle, 1995).

These views are perhaps reflected in the findings of Johnson and Davies (1989) who compared the attitudes of staff with parents. The staff attitudes were generally found to be positive and there was little difference between attitudes towards learning disabled and non-learning disabled people. Parents though appeared to make a distinction between the two groups and perceived their own daughters and sons as being in more need of sex education, pre-marital counselling and abortion than their non-learning disabled peers. Some parents expressed their concern that they would have to raise any grandchildren themselves. It is suggested that they held a more pragmatic approach to the sexuality of their children.

1.3.3. Risk Assessment and Management.

The Royal Society (1992) describes risk perception as being multidimensional and 'personalistic' with a particular risk or hazard having different meanings for different people. In a summary of the Royal Society's definition of risk management, Halstead (1997) describes it as a process by which decisions are made to accept a known or assessed risk, and/or the implementation of actions to 'reduce consequences or

probability of occurrence.’ The development of a risk management strategy it is suggested therefore, requires a complex process of assessing and balancing both harm and benefit.

A distinction is made by Milner and Campbell (1995) between clinical and statistical prediction when assessing risk of violence. *Statistical* prediction involves predicting an individual’s behaviour on the basis of how others have acted in similar situations or on an individual’s similarity to members of violent groups, whereas *clinical* prediction is based on professional training, professional experience and observation of a particular client. Although violence is of course a different area of risk assessment, it can be fairly easily conceptualised within the area of sexuality. The main areas of concern within the research concerning people with learning disabilities and sexuality appear to be within sexual abuse, sexual health and sexual offending. These areas will now be examined more closely.

1.3.4. Sexual Abuse and Risk.

It is only in recent years that the extent of sexual abuse of people with learning disabilities has been acknowledged as, in the past it has been a ‘contentious’ issue and one which has often been met with denial and resistance (Brown, Stein and Turk, 1995). Subsequently, definitions and data gathering are described as being originally designed to give the most ‘conservative’ and ‘least contestable’ figures. Furthermore there have been specific difficulties in investigating incidence of sexual abuse among this client group. These difficulties include: different research methodologies that can affect the incidence and prevalence reported; defining sexual abuse for adults where consent issues may also need defining and clarifying; assessing the reliability and validity of cases where there is little or no corroborating evidence (Turk and Brown, 1993).

A two year incidence survey of the sexual abuse of adults with learning disabilities carried out by Turk and Brown (1993) found that there was a wide variation in the number of cases reported by different agencies. It is suggested that there is a need to develop competencies in investigating reported incidents and providing support for victims of sexual assault, as well as developing preventative strategies.

A second two year survey (Brown et al, 1995) confirmed the pattern of abuse indicated by the first study. These were that both women and men were at risk of abuse, that the perpetrators were predominantly men and were usually known rather than strangers. Additionally, the second study also found that there was a significant increase in the proportion of cases of abuse reported of men with learning disabilities. It was again suggested that service agencies had not developed co-ordinated systems for reporting or recording instances of sexual abuse.

Similarly, a prevalence study of sexual abuse of adults with learning disabilities referred for sex education (McCarthy and Thompson, 1997) found that the rate of abuse was significantly higher for women than men. Almost all the perpetrators were men and the majority were men with learning disabilities or the victim's father. The findings also suggested that responses to the abuse were generally weak although there was some evidence that the abuse of men was taken more seriously.

Issues of consent and mutuality mean that - as mentioned previously - the investigation of abuse and exploitation can be complex and far from clear-cut. A useful description of the difficulties for many professionals working in this field is given from a social worker's perspective (George, 1997). Staff are described as 'walking a tightrope' between their professional responsibilities and the law on the one hand, and the clients' rights and wishes on the other. Conflicting factors often need to be weighed, an example being that a relationship the practitioner regards as sexually exploitative may be experienced as fulfilling for the client.

Besides masturbatory activity most sexual behaviour involves two people and therefore consent and /or mutuality is a key issue. In assessing consent the main factors are described as being twofold - whether the person *did* and whether they *could* give consent (Brown and Turk 1993). A judgement therefore has to be made in deciding the latter as to whether the person had the ability to consent to sexual relationships in general and / or was able to do so without undue pressure. Factors which may pressurise the person and prevent any real choice include: the presence of a parental or familial relationship between the people involved; the presence of a caretaking or custodial relationship between the people involved; the use of force by the first person including the use of a weapon, and the presence of a power imbalance between them.

1.3.5. Sexual Health and Risk.

The changes in the philosophy of services for people with learning disabilities can be seen to have had a direct relevance to people's sexual and emotional lives and to sexual health and risk (Cambridge, 1994). A different set of sexual, emotional and health risks are faced by people now living in the community. This is due to the fact that people are perhaps more exposed now to the risks faced by everyone in the community, rather than the specific risks of exploitation and abuse traditionally associated with institutions (Crossmaker, 1991).

With the movement towards 'normalisation' the issue of sexuality for people with learning disabilities is described as moving towards a concern for the rights of the individual and a recognition of 'the inherent sexuality of human beings, impaired or otherwise' (Pitceathly and Chapman, 1985). This includes the right of individuals to make decisions that may affect their lives. More recently, Cambridge (1997) discusses the issues concerning clients who might be at risk of HIV or AIDS. The right to sexual expression is described as including 'informed risk taking' in relation to HIV infection when this has been assessed. Consequently, if the individual is able to understand the

potential implications of unsafe sex then it is felt that there is only limited scope for intervention.

Similarly, the responsibility of protection would be a priority if the person is not able to understand the implications of their behaviour and / or is not able to give informed consent to sex. It is emphasised that service policies should set standards and principles for practice which aim to help individuals enjoy *healthy* and *safe* sexual lives. Additionally, a service which ‘knowingly’ allowed someone to cause physical or sexual harm to another person would be ‘failing’ in its duty of care.

McManus and Bainbridge (1995a) though feel that within services there is an ethos of ‘protectionism’ concerning sexuality issues for people with learning disabilities, which ‘sits uneasily’ with attempts to value sexual rights. In a later article they state that the main questions for service providers are: who has the right to determine whether a choice is healthy or not; whether someone should take it; and what is the role of professional staff in this? (McManus and Bainbridge, 1995b).

Cambridge (1996) examined the issues involved in assessing and meeting the needs of services in HIV and learning disabilities. It was found that risk assessment and risk management skills within services were poorly developed (although it is acknowledged that this may reflect the skills of the clients in question in hiding their behaviours and their reluctance to talk with staff about what they did). It is further suggested that most providers did not hold a ‘refined understanding’ of HIV, safer sex or the competence to provide educational input.

Similarly, in an earlier study identifying the actions taken by staff for male clients who were identified as being at risk of HIV, there was a great variation in the actions taken, and little evidence to suggest that responses were determined by individual men’s risk (Cambridge, Davies, Nichol, Morris and Corbett, 1993). Thompson, (1995) describes the

service provision in this area as being a 'lottery' and not acceptable on a matter of 'such importance.'

1.3.6. Sexual Offending and Risk.

The issue of men with learning disabilities who sexually abuse is highlighted by some of the findings in these studies, and is perhaps likely to become a more relevant issue due to community living. Interestingly, it is reported that in many services, suspected or known perpetrators of sexual abuse and potential vulnerable victims continue to be congregated together (Turk and Brown, 1993). This is likely to complicate the issues for staff who may need to be advocating the rights of clients who sexually abuse as well as those who have been sexually abused.

Thompson (1997) statistically analysed the offences committed and responses received by 75 men with learning disabilities who had allegedly perpetrated some form of sexual abuse. Variation was found between the nature of the offences across groups of victims, with people with learning disabilities being found to experience the most serious type of assault. The response of services to the men was found to be correlated to who was abused rather than to the nature of the abuse itself.

Similarly, protection of victims from subsequent abuse was also related to this variable - people with learning disabilities and women staff being found to have the least protection. Interestingly, attempts to isolate factors that might be predictive of sexually abusive behaviour were unsuccessful. An example given to illustrate this is the finding that abusers and non - abusers within the study had themselves experienced sexual abuse at similar rates.

In a review of the literature concerning men with learning disabilities who sexually abuse it is concluded that there is a 'great disparity' in the understanding of this behaviour and the desired responses and treatment (Thompson and Brown, 1997). It is suggested that

these difficulties mean that men with learning disabilities are very vulnerable to the influences of individual service - providers and raises ethical issues concerning their rights.

Brown and Turk (1993) make the point though that the 'sanitised' version of independent living and a sometimes 'overzealous and poorly informed' interpretation of normalisation has led to services becoming 'blinkered' to sexual offending by some people with learning disabilities. This is explained in terms of a fear of possibly reactivating society's prejudices and myths that people with learning disabilities are oversexualised and disinhibited. As a consequence it is suggested that people with difficult sexual behaviour have rarely received specialised services and their victims had little or no recognition or support.

1.4. The Present Study.

The aim of this study is to examine the extent to which professional staff working in community learning disability teams are promoting of clients having sexual relationships and factors that might influence this. It is suggested in the literature that professional staff may be more positive in their attitudes towards clients having sexual relationships than carers (Murray and Minnes 1994, Murray and McDonald 1995). Previous work in this area has concentrated predominantly on the attitudes of care staff and parents.

The literature suggests that to a certain extent decisions made concerning the client and issues of sexuality are influenced by the individual values and experience of the professionals / carers involved. McManus and Bainbridge (1995) state that staff working with this client group show too much 'protectionism' towards their clients. To what extent then, does this 'protectionism' exist in the area of sexuality and people with learning disabilities?

According to Milner and Campbell (1994) two important factors in the process of making decisions based on risk are professional training and professional experience. Does professional knowledge and experience affect decisions made regarding issues of sexuality and clients with learning disabilities? Brown and Turk (1993) suggest that services are increasingly having to deal with the ‘reality’ of sexual abuse and the difficulties caused by inappropriate behaviour. Is there a difference in how protective or promoting staff become with experience? Is this influenced by the type of experience they have had in dealing with these issues?

If the individual has had more experience dealing with issues of abuse, will they become more protective towards their clients? Similarly, if the participant has had more experience advocating rights, will that mean that they are more promoting of clients having sexual relationship? What factors does the individual feel might have influenced any changes in how promoting or protective they are of clients?

In this study, ‘experience’ will be separated into three areas:

1. Knowledge around issues of sexuality (and particularly the law).
2. Years of working with this client group.
3. Experience of working with specific issues concerning clients and sexuality.

The hypotheses are as follows:

Hypothesis 1.

The more knowledgeable the participant is the more informed will be their appraisal of risk.

Hypothesis 2.

The more experience the participant has had in responding to potential harm / health concerns the more protective they will be of clients when making decisions concerning risk.

Hypothesis 3.

The more experience the participant has had in advocating / promoting rights the more promotional they will be of clients in sexual relationships.

Hypothesis 4.

The type and amount of experience the participant has in dealing with issues concerning sexuality will relate to their appraisal of risk.

Hypothesis 5.

There will be a change in how promoting / protective the participant is from first working with the client group to the present time dependant on experience.

Qualitative question:

When the participant has expressed a change over time in how protective / promotional they are, the factors involved in this change will include knowledge, experience of working with clients concerning particular issues and overall experience of working with this client group.

Hypothesis 6.

The more experience the participant has had in responding to sexual offenders the more protective they will be of potential victims / society.

2. Method.

2.1. Participants.

2.1.1. Inclusion criteria.

Staff included in this study worked within community learning disability teams, and were professionally qualified members of the team. Staff groups included clinical psychologists, social workers, and nurses qualified to work with people with learning disabilities.

2.1.2. Recruitment sources.

Participants were recruited through community learning disability teams within one regional health authority. Thirteen NHS Trusts were contacted within the region.

2.2. Description of the Region.

The regional health authority within which the teams are based is extremely varied in its make up, consisting of large inner city areas as well as small towns and rural areas. Socio-economic factors therefore vary greatly within the region.

2.3. Procedure.

2.3.1. Ethical Considerations.

As more than four NHS Trusts were involved in the research, ethical approval was sought and gained from the regional ethics committee.

2.3.2. Recruitment.

The head of each learning disability speciality service within the region was contacted (see Appendix 2) and permission sought to contact learning disability teams. Thirteen teams agreed to participate. An information sheet (see Appendix 3) outlining the research and highlighting issues of confidentiality was included. A copy of the questionnaire was also included for reference. The final version of the questionnaire had not at this time been completed, and due to time constraints it was necessary to carry out recruitment before the piloting process was completed. The fact that there might be changes to the questionnaire before final distribution was explained on the questionnaire itself.

Following a positive reply from each head of speciality, an information sheet and copy of the questionnaire was sent to the manager of each team. Each team manager was then contacted by telephone and if the team agreed to take part further information was obtained as to the amount of questionnaires to send to the team. The appropriate number of questionnaires with an attached information sheet and stamped addressed envelope were sent to each team. These were to be distributed by either the team leader or the team administrator.

One team required a visit to be made to their monthly multidisciplinary team meeting to present information concerning the research and request participation from the team members. Questionnaires were distributed to members of the team. A stamped addressed envelope was again included for each questionnaire.

One hundred and ninety questionnaires were distributed to fifteen teams.

2.3.3. Questionnaire Design (see Appendix 4):

The questionnaire comprises four sections.

Section 1: 'Experience.'

This comprises seven questions. Questions one to five concern demographic information including professional background and also ask how much training the participant has received in sexuality issues and whether they have been involved in teaching other staff about these issues.

Question six requested participants to estimate the number of clients with learning disabilities they had worked with involving certain issues (ten in all) these included clients experiencing heterosexual relationships, dealing with issues of abuse and sexual health. A choice of four different answers was given ranging from 'none' to '11+'.

Question 7 asks whether overall the participant feels that their experience has been more towards advocacy / promoting the rights of people with learning disabilities to sexual relationships, or investigating / responding to potential harm, abuse or illness in the person concerned and / or protecting alleged victims. A five point scale is used beginning with 1 and ending at 5. One is described as 'more advocating / promoting rights' and 5 is described as 'more responding to potential harm / health concerns or protecting victims. Three is described as 'balanced experience.'

Section 2: Respondents views on their likelihood of promoting / protecting within relationships.

This section comprises four questions. The introduction to the section explains that the questions are asking whether the participant feels their attitudes towards clients and sexuality issues have changed throughout their career, becoming either more polarised

towards advocacy of the client's rights or more protective of society or the person from abuse/harm.

Each of the four questions is divided into two parts. The first part asks the participant to rate how promotional / protective they were at the beginning of their career. A five point scale is used beginning with 1 and ending at 5. One is described as 'promotional' and 5 as 'protective.' Three is described as 'neutral.' The second part of the question asks the participant to rate how promotional / protective they are of the client at the present time, using the same scale.

The questions are concerned with the following issues:

Question 1 - Where the participant has been involved in the rights of individual clients to have sexual experience.

Question 2 - Where the participant has been involved in issues concerning couples in sexual relationships and issues of mutuality and consent.

Question 3 - Where the participant has been involved in issues concerning possible abusers with learning disabilities.

Question 4 - Where the participant has been involved in issues concerning people with learning disabilities who are possible victims of abuse.

The participant is then asked to describe - where relevant - any factors that had led to changes in how promotional / protective they are.

Section 3 'Knowledge'

This section comprises fifteen questions concerning sexuality issues. A statement is made and a 'true' or 'false' response is required. The questions were chosen to reflect a wide variety of issues concerning sexuality, including those that affect the general population and those that relate specifically to people with learning disabilities. This reflects the law as mentioned previously (Gunn, 1996). A wide variety of issues were covered including consent, sexual offending, fertility and confidentiality.

The questions were devised in collaboration with a clinical psychologist who specialises in the area of sexuality and people with learning disabilities and teaches professionals and trainees in issues surrounding this subject.

The questions are as follows: (For the answers to the questions and the appropriate references see Appendix 5).

1. People with learning disabilities are biologically more fertile.
2. The children of parents who have learning disabilities are more likely to have learning disabilities than those of parents of average IQ.
3. People with learning disabilities require permission by law to marry.
4. Crimes committed by people with learning disabilities are more likely to be of a sexual nature.
5. An abortion or sterilisation may only be performed on an adult with their consent.
6. Under the Sexual Offences Act (1956) it is an offence:

- a. For a man to have sexual intercourse with a woman with a severe learning disability.
 - b. To take a woman with a severe learning disability away from a parent or guardian with intent to allow unlawful sexual intercourse with a man.
7. Teaching someone to masturbate can be construed as sexual assault.
8. Male staff and managers are legally forbidden from having sexual intercourse with female clients being treated for mental disorder.
9. Female staff and managers are legally forbidden from having sexual intercourse with male clients being treated for mental disorder.
10. Recent changes to legislation means that the age of consent for men to engage in homosexual acts has moved from 21 years to 16 years. NB The questionnaires were completed up to eight weeks before the recent vote in the House of Commons to reduce the age to 16 years.
11. There is a legal obligation to keep the HIV status of users confidential on the part of:
- a. GUM clinics.
 - b. GP's.
 - c. Services for people with a learning disability.
12. A person with a learning disability living in residential accommodation is most likely to be abused by another resident.

Section 4: ‘Scenarios.’

This section is made up of seven scenarios. The scenarios involve issues concerning sexuality and were devised to include the experiences described in section 1 question 6, in liaison with a clinical psychologist who teaches trainees and other professionals in issues concerning sexuality and people with learning disabilities. These scenarios are as follows:

Scenario 1 - Clients experiencing a heterosexual relationship (Section 1 question 6a and 6c).

Scenario 2 - Dealing with issues of abuse (Section 1 question 6d).

Scenario 3 - Supporting gay/lesbian relationships (Section 1 question 6b and 6c).

Scenario 4 - Couples/marriage, parents with a learning disability (Section 1 question 6g and 6f).

Scenario 5 - Investigating consent/mutuality, dealing with issues of inappropriate behaviour (Section 1 question 6c and 6e).

Scenario 6 - Couples/marriage (Section 1 question 6g).

Scenario 7 - Sexual health (Section 1 question 6h and 6c).

Each scenario is accompanied by two questions each of which have a rating scale of 1-5. The questions vary according to the content of the scenario as do the rating scales. For example the rating scales for scenario 7, question ‘a’ range from ‘not at all’ to ‘a great deal’ and 7b from ‘unconcerned’ to ‘extremely concerned.’

Each of the two questions asks the participant to answer from a different perspective. For example in the case of scenario 4 - the married couple who want to have children - the respondent is asked firstly to rate how promoting they would be of the rights of the couple to have a child (rating 1 as ‘not at all’ and 5 as ‘a great deal.’) and secondly to rate how concerned they would be for the welfare of any children they might have (rating 1 as ‘unconcerned’ and 5 as ‘extremely concerned’).

Each rating scale is scored as ‘most promoting’ at one end and ‘most protective’ at the other. This varies according to the wording of the scale for example, for Section 4 question 3a, 5 (‘a great deal’) is the most promoting response and for 3b, 1 (‘not at all’) is the most promoting response. A promoting and protecting score is calculated for each scenario. This was calculated depending on how the scale was orientated and meant that some scores had to be reversed so that 5 would equal 1 and vice versa.

The ratings for the scenario scores are as follows:

1a: 1= most protective, 5= most promoting. 1b: 1= most promoting, 5= most protective.
2a: 1= most promoting, 5= most protective. 2b: 1= most promoting, 5= most protective.
3a: 1= most protective, 5= most promoting. 3b: 1= most promoting, 5= most protective.
4a: 1= most protective, 5= most promoting. 4b: 1= most promoting, 5= most protective.
5a: 1= most promoting, 5= most protective. 5b: 1= most promoting, 5= most protective.
6a: 1= most protective, 5= most promoting. 6b: 1= most promoting, 5= most protective.
7a: 1= most protective, 5= most promoting. 7b: 1= most promoting, 5= most protective.

2.3.3.1. Pilot Study.

A pilot study was carried out with fifteen participants (four male and ten female). These were clinical psychology trainees all of whom had already completed at least a six month placement in the field of learning disabilities. At least five had also worked in this area as an assistant psychologist prior to commencing training. Rudestam and Newton (1992) suggest that when designing a questionnaire it is useful during the piloting process to ask participants specific questions concerning their experience of completing the questionnaire. Participants were therefore asked to give feedback on the questionnaire as to any difficulties they had encountered in completing it.

Results:

The findings that were relevant in evaluating and improving the questionnaire design will be reported.

Section 1: Question 7:

The mean score was 3.2 indicating that most participants felt that they had had a balanced experience between advocating / promoting the rights of clients to sexual relationships, and responding to potential harm / health concerns or protecting victims.

Section 2 : Questions 1, 2, 3 and 4:

Most of the participants reported difficulty in answering question 4 and indicated that the wording was confusing (only three participants completed the question). Several participants also indicated that there was some overlap in the experiences they reported for question 1 and 2.

Section 3: Knowledge.

The mean knowledge score was 10 - out of a possible 15. The minimum score gained was 8 and the maximum 12. The mean score could be considered as fairly high. This might be due to the fact that teaching sessions on sexuality and people with learning disabilities are part of the training course and it is likely that most of the participants had attended these no more than 18 months previously.

Section 4: Scenarios.

Reliability:

Adequate reliability is described as a precondition to validity, and describes the consistency of the measure (Oppenheim, 1992). Internal consistency is based on the principle that each part of the test should be consistent with all other parts. Cronbach's alpha (Cronbach 1951, cited by Hammond 1995). was developed for use on items measured on continua or rating scales, and gives a measure of reliability. Alpha is related to the average of all the inter-item correlations. The higher the correlations between the items the greater internal consistency is (Hammond, 1995). The reliability coefficient for the scenario scores was .68 which indicates a reasonable level of reliability.

The highest possible scenario score is 70, and the lowest possible score is 14. The higher the score gained the more protective the responses to the scenarios are. The mean score on the scenarios was 47.5. The maximum score gained was 57 and the minimum score 35.

2.3.3.2. Final draft of questionnaire.

As a result of the feedback and findings of the pilot study, the following changes were made to the questionnaire (see Appendix 6 for final version of questionnaire).

Section 1 - Experience.

Question 4 - Participants were given a range of answers to estimate the number of days training they had received in sexuality issues. These ranged from 'none' to 11+.

Question 7 - Moved to section 2.

Section 2.

Definitions of ‘promotion’ and ‘protection’ are given, these were developed from the literature described previously.

Question 1 - This is the original question 7 from section 1.

Question 2 - This now concerns the rights of individual clients to have sexual experiences (as questions 1 and 2 appeared to yield similar information).

Question 3 - Remains the same.

Question 4 - Removed (as participants found it too confusing, and appeared to yield similar information to question 3).

Reliability

Participants were asked after both question 2 and question 3 to describe where relevant, any factors that led to changes in how promotional / protective they are. This qualitative data was coded into categories and then rated by an independent rater. Inter-rater reliability was measured using Cohen’s Kappa statistic K , which is the coefficient of agreement for nominally scaled data (Siegel and Castellan, 1998). A value of 1 indicates perfect agreement, and a value of 0 indicates that agreement is no better than chance. The Cohen’s Kappa statistic K was as follows:

Section 2 question 2:

When the response was ‘more protective’ - $K = .65$

When the response was ‘more promoting’ - $K = .62$

Section 2 question 3:

When the response was 'more protective' - $K = .73$

When the response was 'more protective' - $K = .80$

A reasonable to good level of agreement was found.

Section 4 - Scenarios.

Scenario 1 - All the information that might lead the participant to judge that 'Sarah' was at risk in the relationship was removed. She is living independently indicating that she has limited disabilities and is forming a relationship with someone of a similar age and ability. No information has been given to suggest that the relationship is abusive.

The wording of the questions for scenarios 1 and 7 was changed to concentrate more on issues of consent. Names were also included to reflect ethnic diversity.

Reliability.

The Chronbach's Alpha Coefficient for the scenario scores was .60 indicating a reasonable level of reliability.

3. Results.

3.1 Response rate.

One hundred and ninety questionnaires were distributed and seventy eight returned. The response rate therefore was 41 per cent.

3.2 Demographic details.

3.2.1 Gender.

Fifty eight respondents were female (74 per cent) and twenty male (26 per cent).

3.2.2. Professional background.

The participants represented eight different professions (see Figure 1). The three professions most represented were nurses (28 per cent), clinical psychologists (24 per cent) and social workers (15 per cent).

3.2.3. Professional experience.

Working with client group:

The time spent working with this client group since qualifying in a profession ranged from six months to twenty plus years (see Figure 2). Twenty participants (26 per cent) had 1-5 years experience and nineteen participants (24 per cent) had 5-10 years experience.

Figure1: Professional Background

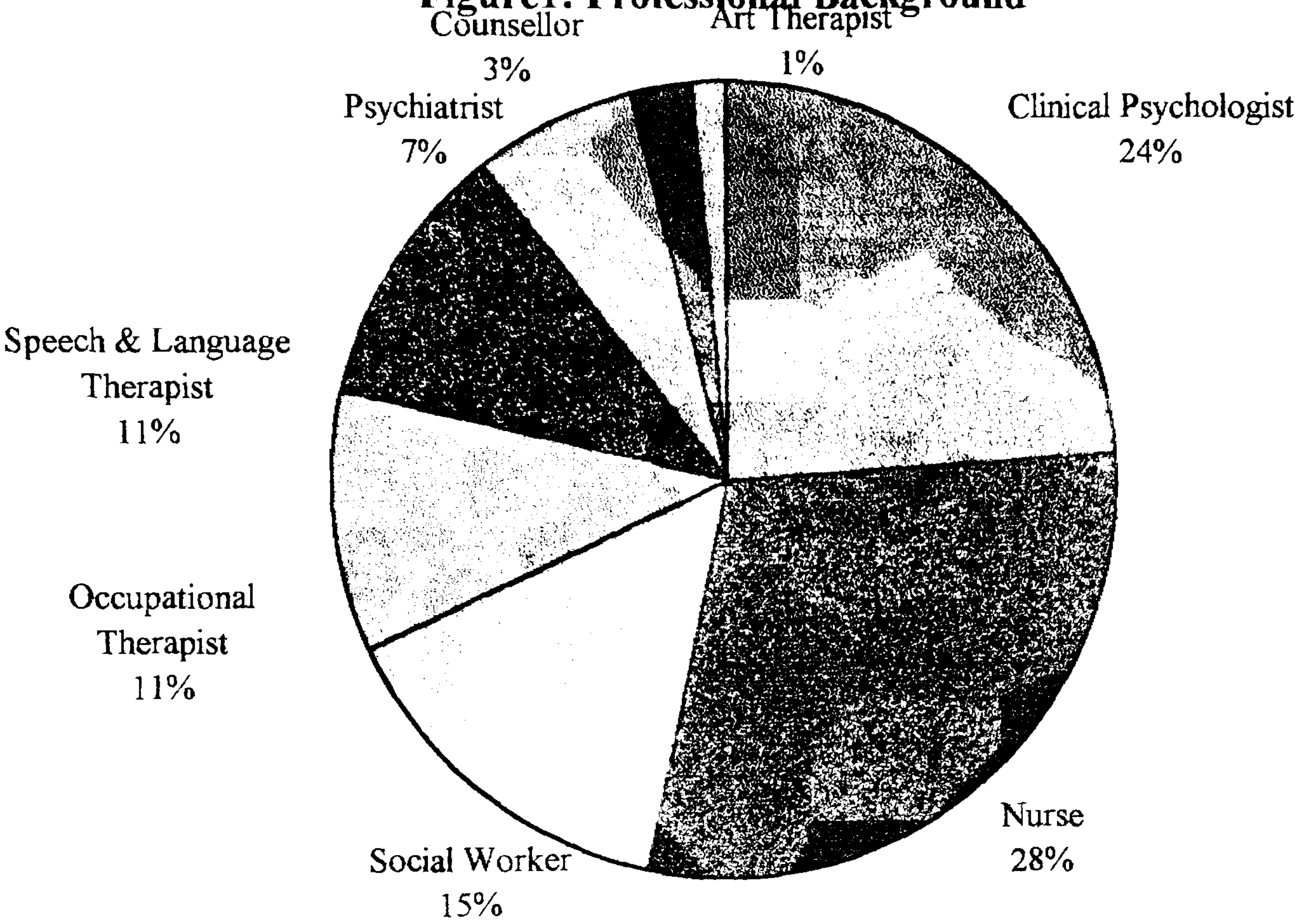
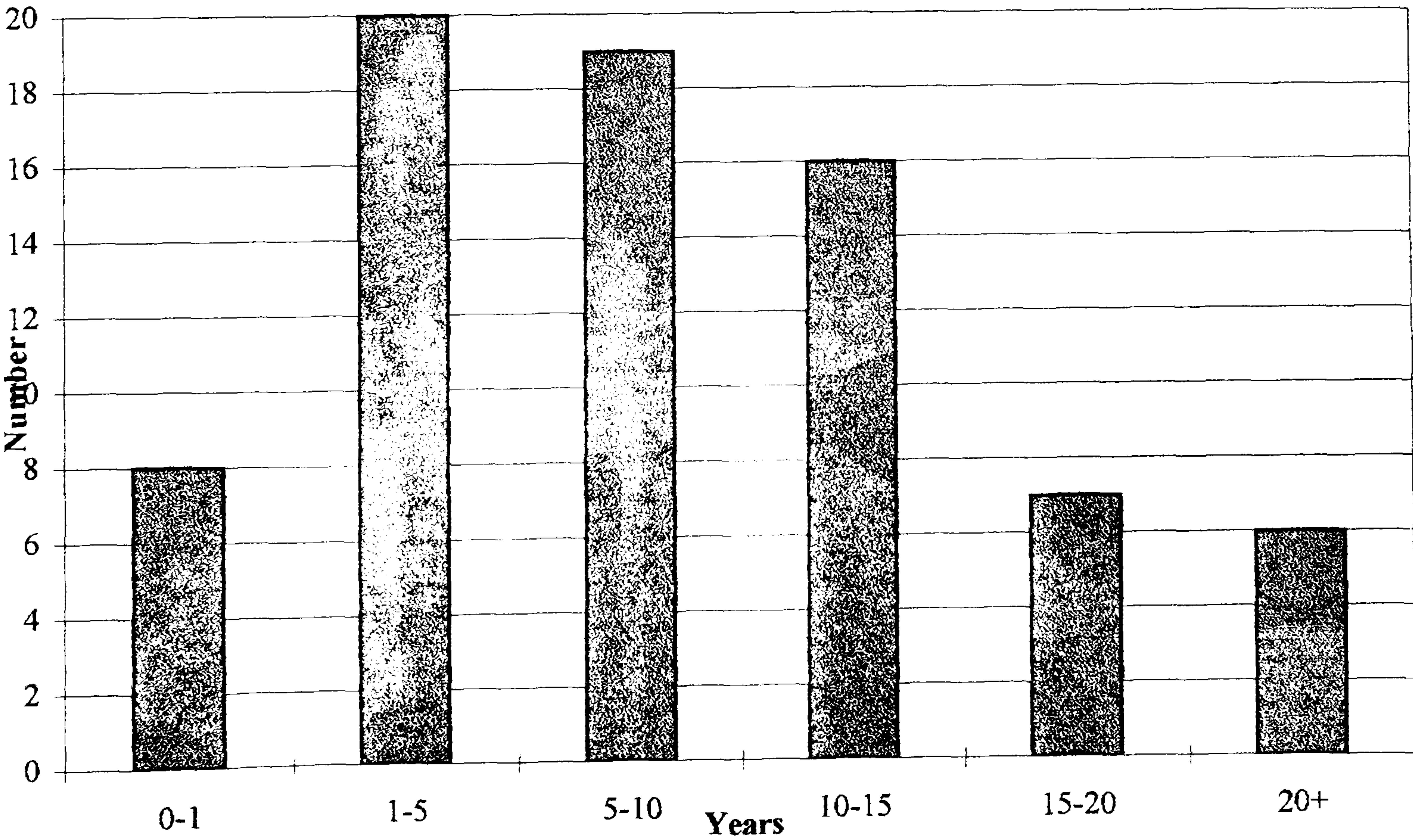


Figure2: Years working with people with learning disabilities



Days of training in dealing with sexuality issues:

Sixty-two participants (79 per cent) reported that they had received further training in issues of sexuality since completing their professional training. Sixteen (21 per cent) reported having no further training in this area since qualifying. Forty-three participants (55 per cent) had received between one and five days training, and eleven (14 per cent) had received eleven or more days training (see Figure 3).

Teaching of issues concerning sexual relationships:

Thirty-eight participants (49 per cent) had been involved in the teaching of care staff, trainees and / or other professionals. Forty participants (51 per cent) had not been involved in teaching sexuality issues.

Experience of working with issues concerning sexuality:

Most participants reported having experience in dealing with heterosexual relationships (75 respondents - 96 per cent) and in dealing with inappropriate behaviour (74 respondents - 95 per cent). The highest number of participants reported having no experience in supporting gay / lesbian relationships (36 respondents - 46 per cent) and in dealing with clients with sexually transmitted diseases including HIV (40 respondents - 51 per cent) - see Figure 4.

3.3. Knowledge scores.

Question 4 was not included in the data as it is now felt that the evidence concerning men with learning disabilities who sexually abuse is too contradictory (Thompson, 1998). The highest possible score for the knowledge section is therefore 14 (see Figure 5). The

Figure 3: Days of Training in Sexuality Issues

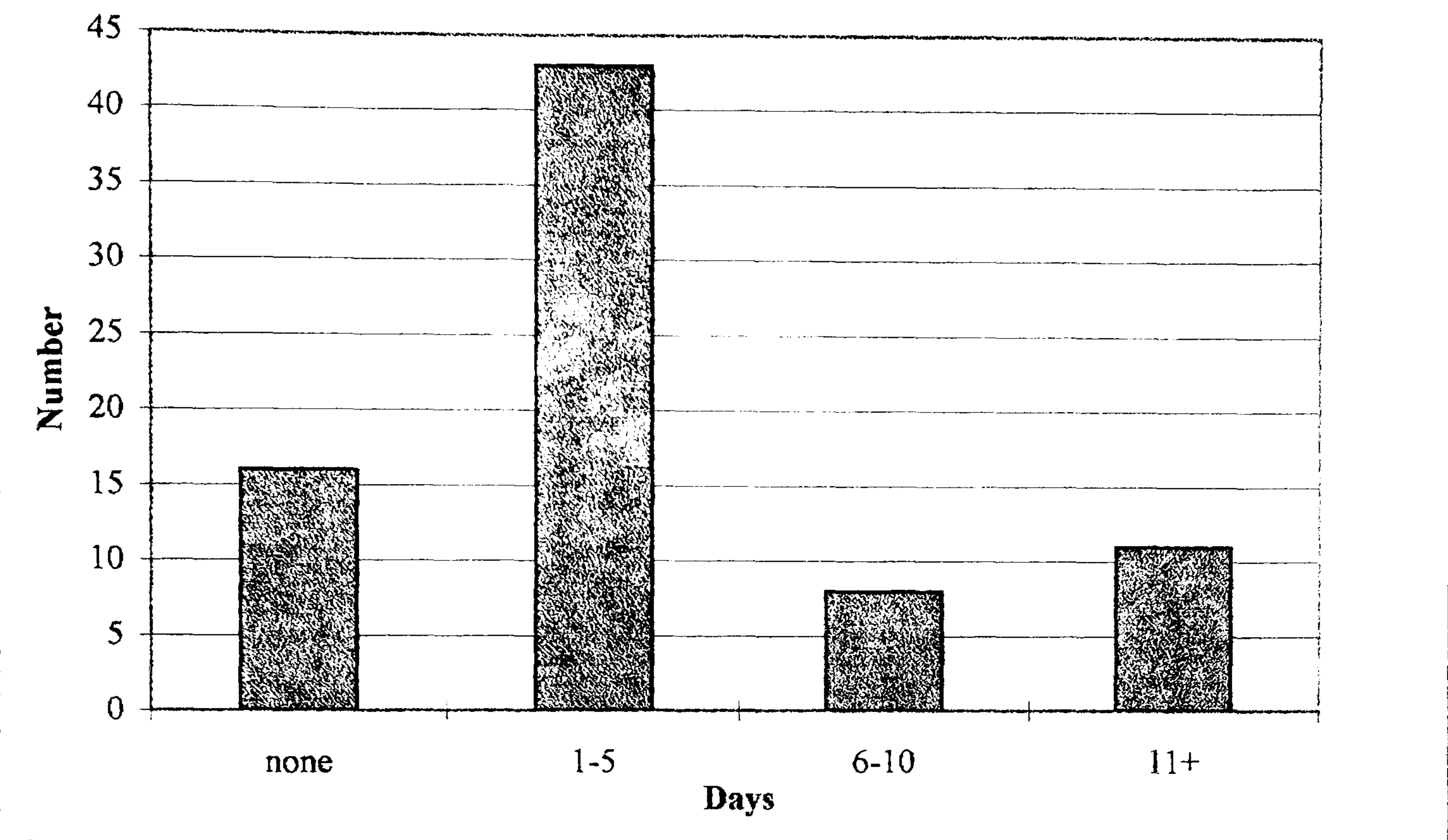


Figure 4: Experience of working with issues concerning Sexuality

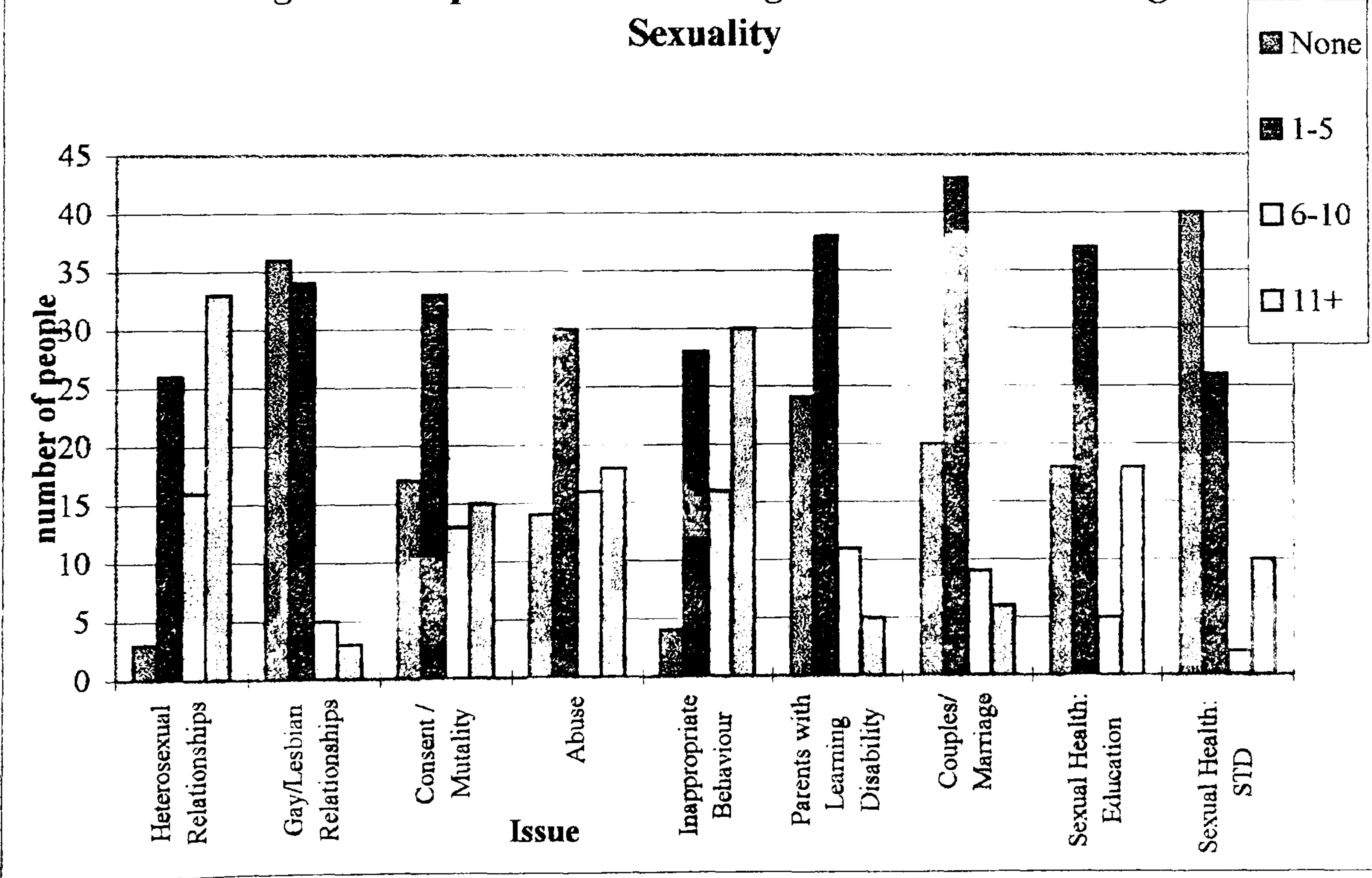


Figure 5: Knowledge Scores

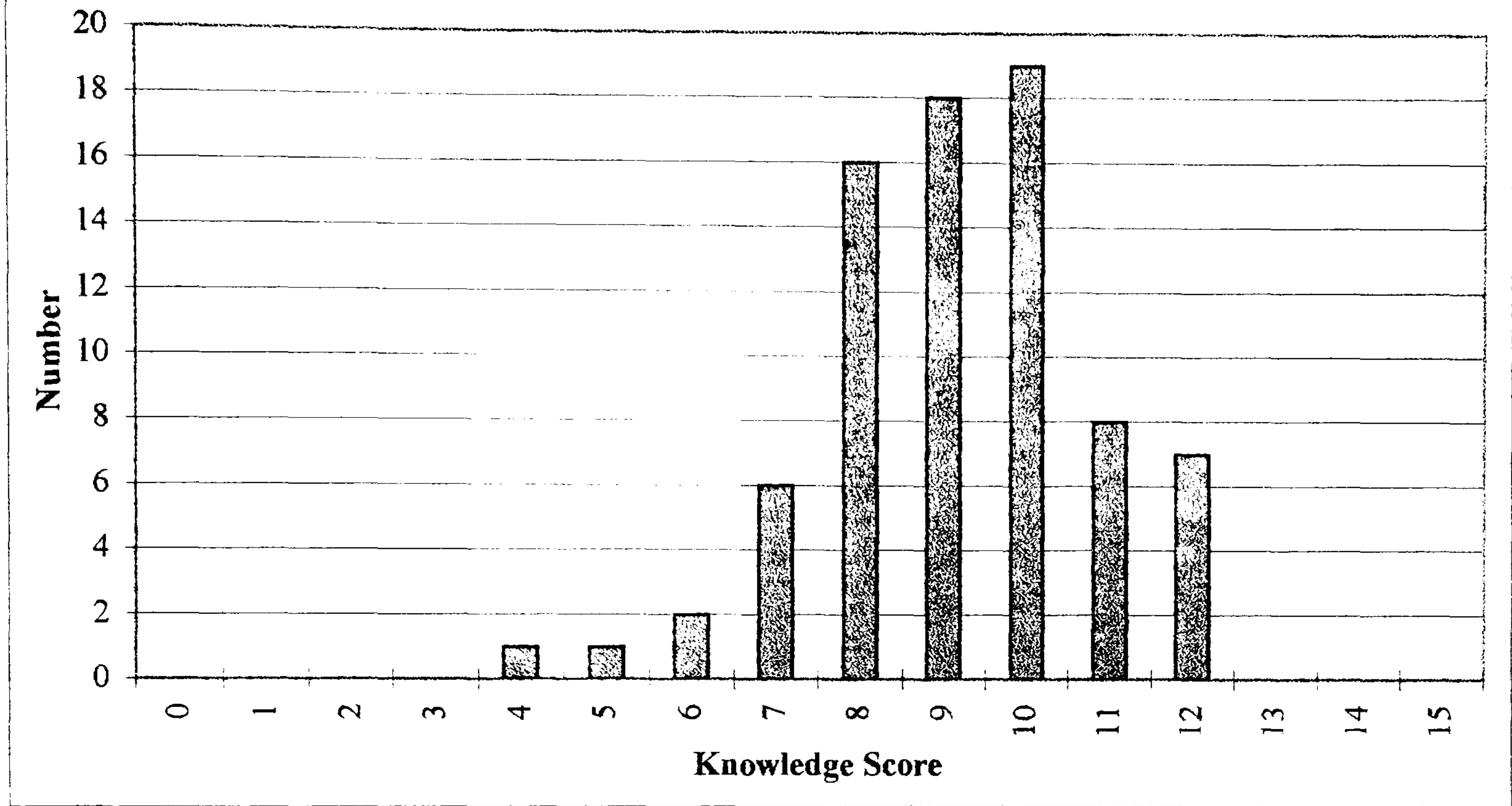
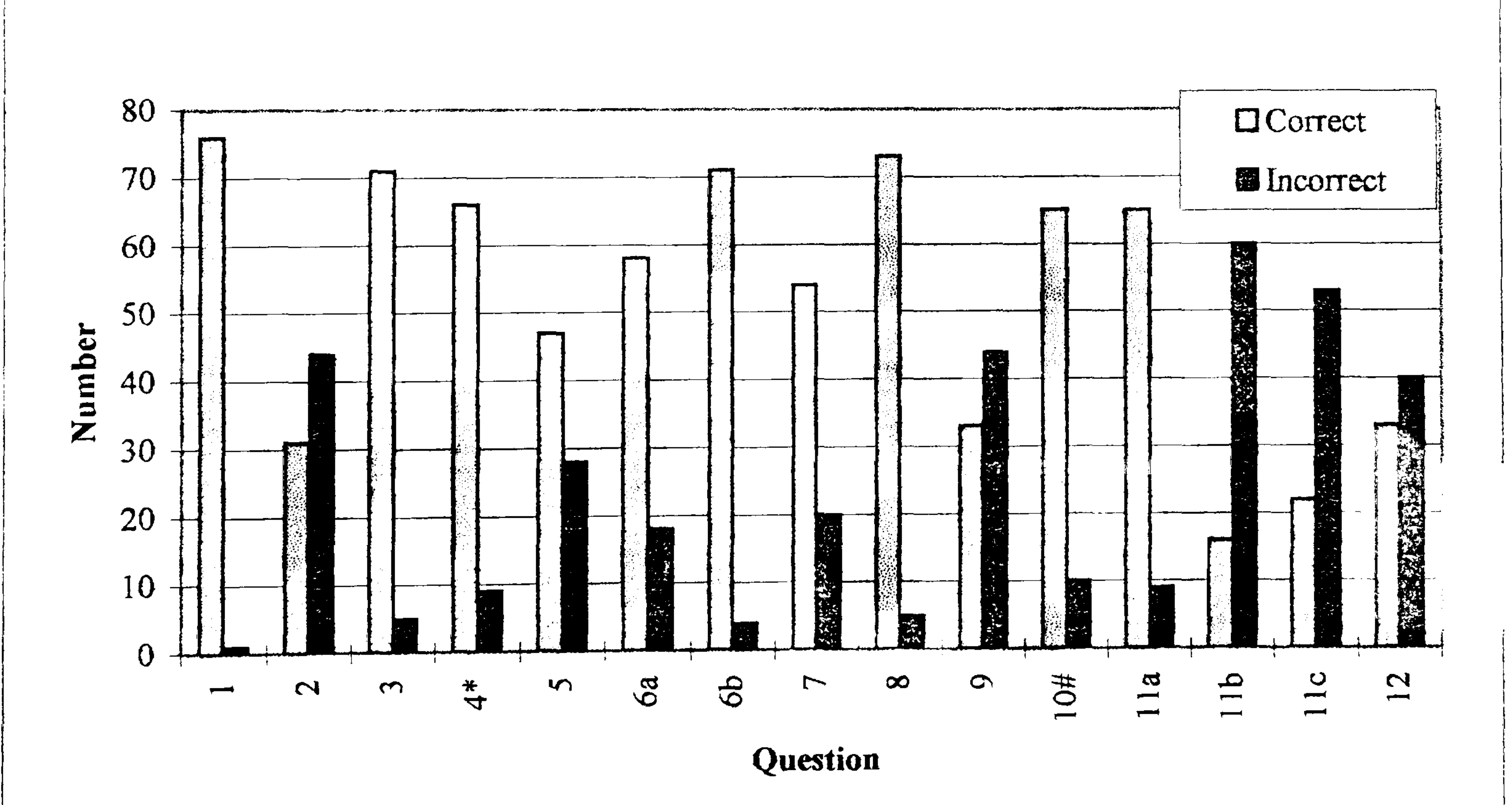


Figure 6: Responses to Knowledge Questions



N.B. * question excluded . # law has since changed (see text)

mean score was 9.1. The highest knowledge score attained by participants was 12 (seven participants) and the lowest was 4 (one participant).

The question that gained the highest number of correct answers was question 1 (are people with learning disabilities biologically more fertile - 77 correct answers) and the question that gained the lowest amount of correct answers was question 11b (is there a legal obligation on the part of GPs to keep the HIV status of users confidential - 16 correct answers) - see Figure 6.

3.4. Scenario Scores:

The scenario which had the highest number of 'protective' scores was scenario 2 (concerning possible abuse) see Figure 7. The scenarios which had the highest number of 'promoting' scores were scenario 1a (concerning the extent to which support would be given to a heterosexual relationship) and scenario 4a (concerning the rights of a couple to have a child). 1b (the extent to which the respondent would be concerned that issues of consent are investigated) had an almost equal number of promoting and protective scores, and scenario 4b indicated that a similar number of respondents were 'quite concerned' about the rights of the child as the number who had been promoting of the right of the couple to have a child.

The highest possible scenario score is 70 and the lowest is 14 (see Figure 8). The lower the score the more promoting the person is and the higher the score the more protective. The highest scenario score was 57 (one participant) and the lowest score was 31 (one participant). The score which the highest number of participants gained was 47 (eleven participants).

Figure 7: Individual Scenario Responses

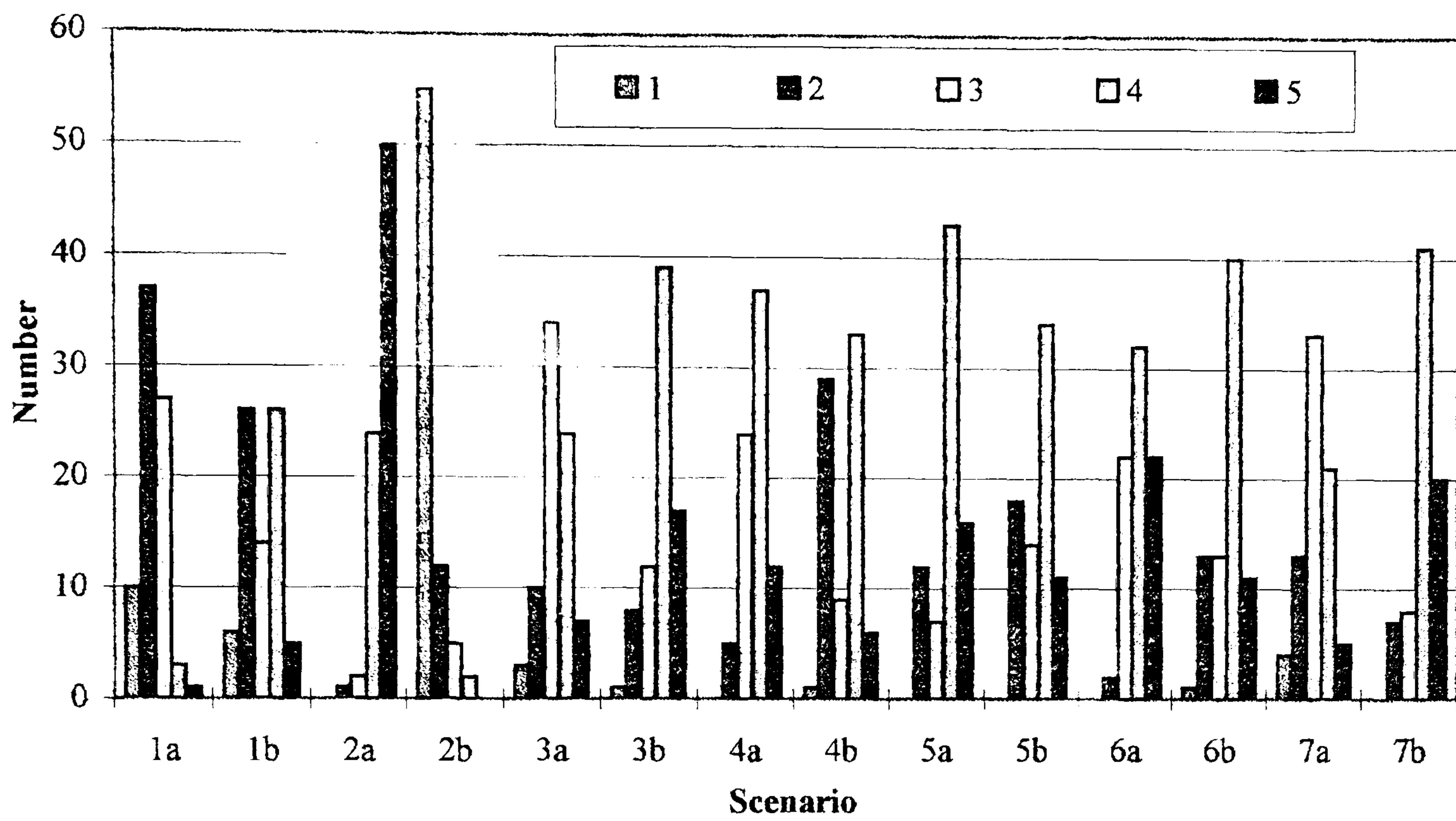
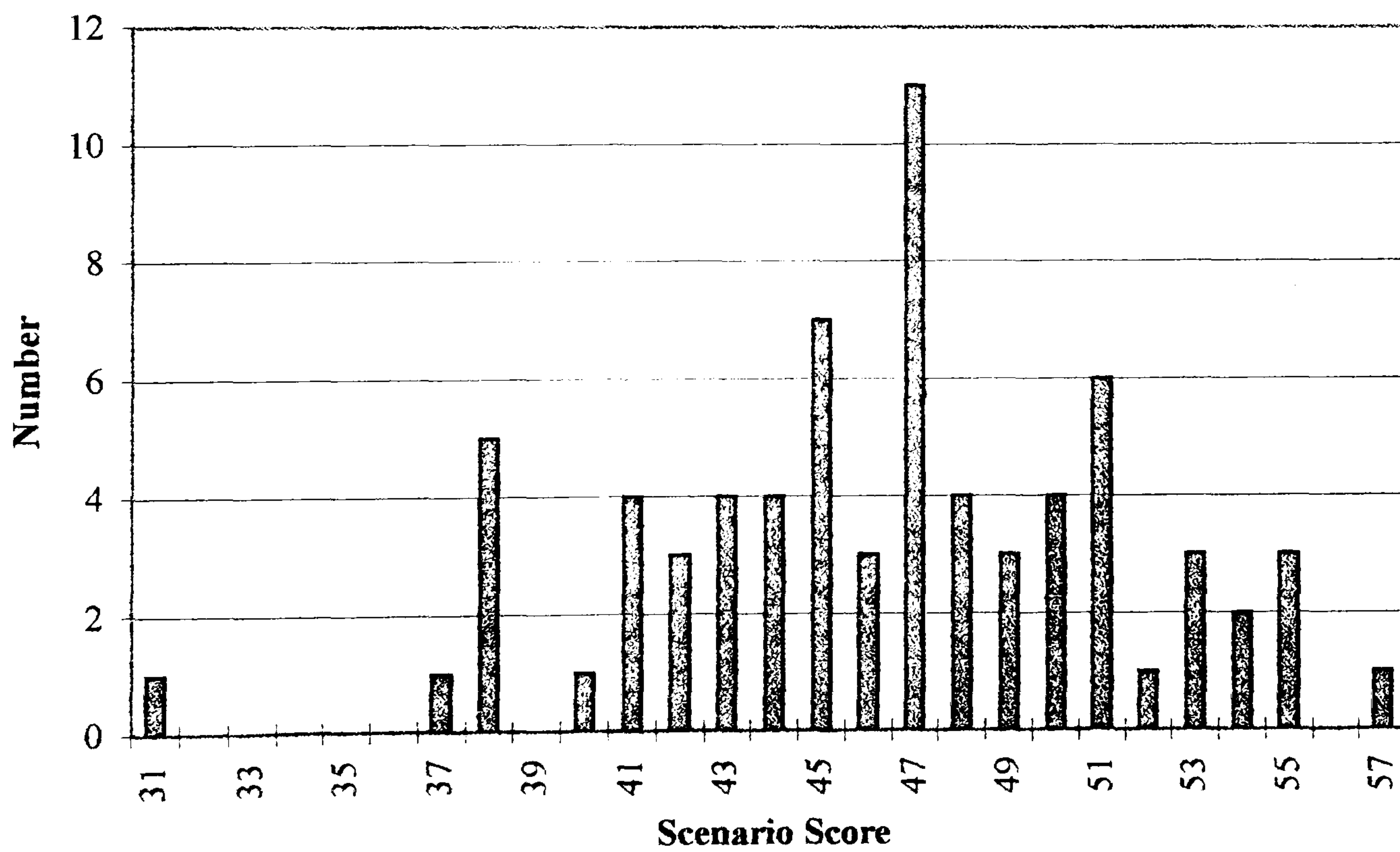


Figure 8: Distribution of Scenario Scores



The mean scenario score was 46.4. If all the questions in the scenario section are scored as 'neutral' then the score would be 42. This figure can therefore be regarded as a 'centre-line' of neither promoting nor protecting.

Missing data:

Seven participants did not answer all the questions in the scenario section. It wasn't possible therefore to give those participants an overall 'promotional' score so the data for these participants was excluded from the scoring of this section.

3.5. Statistical Analysis:

Pearson correlations were used in the statistical analysis of the data. Although some of the individual scenario scores indicate a somewhat skewed distribution - for example the scores for scenario 2b (see figure 7) - the total scenario scores are roughly normally distributed in the sample. Although the data could be described as ordinal, the decision to use Pearson rather than Spearman correlations was made on the basis of this overall distribution (see figure 8).

NB: All correlation significance levels are for a 2-tailed test at $\alpha = 0.05$ unless otherwise stated. The sample size (n) varies slightly between computations due to missing data.

Hypothesis 1 - The more knowledgeable the participant is the more informed will be their appraisal of risk.

A Pearson correlation was carried out between overall knowledge score and scenario score. A significant positive correlation was found which implies that the more

knowledgeable the professional is, the more protective their behaviour ($r = 0.30$, $p = 0.01$, $n = 71$).

A Pearson correlation was performed between the knowledge scores and the sum of question 6a, b, f, and g. These issues were chosen as they relate specifically to dealing with relationships. A significant positive correlation was found, indicating that the more experience the individual has working with sexuality issues the more knowledge they have ($r = 0.25$, $p = 0.025$, $n = 78$).

A one-way ANOVA was carried out comparing total knowledge scores within the three professional groups that had the most respondents. This parametric test was used as the knowledge scores approximated to a normal distribution (see figure 5). In addition, Levene's test for homogeneity of variance was performed on these data and was not significant ($F = 0.25$, $df = 2$, $p = 0.78$). That is, the homogeneity of variance condition was satisfied.

The three professional groups that were compared were clinical psychologists, social workers and nurses. The means (and standard deviations) of the scores for each group were: 9.89 (1.37); 9.64 (1.69); 9.00 (1.60) respectively. The result of the ANOVA was not significant ($F = 1.74$, $df = 2$, $p = 0.19$). This indicates that there was no significant difference between knowledge scores for people with different professional backgrounds.

Hypothesis 2 - The more experience the participant has had in responding to potential harm / health concerns the more protective they will be of clients when making decisions concerning risk.

The following Pearson correlations were performed between:

Section 2 question 1 and section 2 question 3. This was not significant ($r = 0.19$, $p = 0.13$, $n = 78$).

Section 1 question 6c (experience in investigating consent/mutuality) and scenario 2a (the scenario dealing with possible abuse). This was not significant ($r = 0.18$, $p = 0.13$, $n = 77$).

Section 1 question 6d (experience in dealing with issues of abuse) and scenario 2 question a. This was not significant ($r = 0.18$, $p = 0.12$, $n = 78$).

These results indicate that within this data set, there is no evidence to support the hypothesis that the more experience the participant has had in responding to potential harm / health concerns the more protective they will be of clients when making decisions concerning risk.

Hypothesis 3: The more experience the participant has had in advocating / promoting rights the more promotional they will be of clients in sexual relationships.

The following Pearson correlations were performed between:

Section 2 question 1 (overall experience gained in promoting / protecting) with section 2 question 2 (how promotional / protective of individuals having sexual relationships). This was not significant ($r = 0.19$, $p = 0.12$, $n = 78$).

Section 2 question 1 and scenario 3a (homosexual relationship). This was not significant ($r = 0.16$, $p = 0.18$, $n = 78$).

Section 2 question 1 and scenario 3b. This was not significant ($r = 0.02$, $p = 0.88$, $n = 77$).

Section 2 question 1 and scenario 1a (heterosexual relationship). This was not significant ($r = 1.31$, $p = 0.25$, $n = 77$).

Section 2 question 1 and scenario 1b. This was not significant ($r = 0.05$, $p = 0.67$, $n = 77$).

These results indicate that within this data set, there is no evidence to support the hypothesis that the more experience the participant has had in advocating / promoting rights the more promotional they will be of clients in sexual relationships.

Hypothesis 4: The type and amount of experience the participant has in dealing with issues of sexuality will relate to their appraisal of risk.

Each ‘experience’ in section 1 question 6 was matched with the appropriate scenario as described in the method section. Pearson correlations were performed on the data, the results are described in Table 1.

Table 1: Correlations performed between type of experience and scenario scores.

Type of Experience	Scenario	r	p	n
6a - Clients experiencing heterosexual relationships	1 (a)	0.00	0.98	78
	1 (b)	-0.28	0.02*	78
6b - Supporting gay/lesbian relationships	3 (a)	-0.09	0.45	78
	3 (b)	-0.02	0.88	78
6c - Investigating consent/mutuality	1 (a)	-0.04	0.76	78
	1 (b)	-0.18	0.12	77

Type of Experience	Scenario	r	p	n
6c - Investigating Consent/mutuality	3 (a)	0.08	0.49	78
	3 (b)	-0.07	0.53	77
	5 (a)	0.05	0.64	78
	5 (b)	0.13	0.27	77
	7 (a)	0.14	0.24	76
	7 (b)	-0.15	0.18	76
6d - Dealing with issues of abuse.	2 (a)	0.21	0.07	77
	2 (b)	-0.18	0.13	74
6e - Dealing with inappropriate behaviour	5 (a)	0.03	0.82	78
	5 (b)	0.20	0.08	77
6f - Parents with a learning disability	4 (a)	0.03	0.77	78
	4 (b)	0.09	0.45	78
	6 (a)	0.02	0.89	78
	6 (b)	-0.08	0.47	78
6g - Couples / marriage	6 (a)	0.09	0.94	78
	6 (b)	-0.11	0.33	78
	4 (a)	0.08	0.47	78
	4 (b)	-0.17	0.09	78
6h (i) Sexual health - education / preventative 6h (ii) Sexual health - sexually transmitted diseases including HIV	7 (a)	0.15	0.19	76
	7 (b)	-0.19	0.10	76
	7 (a)	0.10	0.36	76
	7 (b)	-0.27	0.02*	76

* Correlation is significant at the 0.05 level.

The results indicate that the more experience the participant has in dealing with issues surrounding clients having heterosexual relationships the more promoting they are. The

results also indicate that the more experience the participant has in dealing with issues of sexual (sexually transmitted diseases including HIV) the less protective they were of the client in the scenario concerning these issues.

A Pearson correlation was performed between the overall experience (in months) the participant had of working with clients with learning disabilities and the scenario scores. This was not significant ($r = 0.12$, $p = 0.34$, $n = 69$).

Hypothesis 5: There will be a change in how promoting / protective the participant is from when they first worked with the client group to the present time dependant on experience.

The mean score for section 2 question 2a was 2.68 and the mean score for section 2 question 2b was 2.53. This indicates that the participants became more promotional over time of the rights of individual clients to have sexual experiences. A paired samples t-test was carried out to test whether there was a significant difference between the means of the two sets of scores. This found that there was no significant difference between how promotional staff rated themselves as being at the beginning of their career and at the present time. The mean difference was -0.15 ($t = -0.98$, $p = 0.33$, $df = 74$).

The mean score for section 2 question 3a was 3.42 and the mean score for section 2 question 3b was 2.20. This indicates that participants became more promotional over time of the rights of possible abusers with learning disabilities. A paired samples t-test was again carried out to test whether there was a significant difference between the means of the two sets of scores. This found that there was no significant difference between how promotional staff rated themselves as being at the beginning of their career and at the present time. The mean difference was -1.22 ($t = -1.87$, $p = 0.06$, $df = 62$).

For section 2 question 2: 38 participants reported that they had not changed (49 per cent)
18 reported that they had become more promotional (23 per cent)

22 reported that they had become more protective (28 per cent)

For section 2 question 3: 51 participants reported that they had not changed (65 per cent)

8 reported that they had become more promotional (10.1 per cent)

17 reported that they had become more protective (22 per cent)

2 participants did not answer this question.

The following Pearson correlations were performed between:

The change in the score in section 2 question 2 (a and b) and experience in years. This was not significant ($r = -0.22$, $p = 0.61$, $n = 73$).

The change in the score in section 2 question 2 (a and b) and experience working with different issues. This was not significant ($r = 0.01$, $p = 0.91$, $n = 75$).

The change in the score in section 2 question 3 (a and b) and experience in years. This was not significant ($r = -0.06$, $p = 0.66$, $n = 61$).

The change in the score in section 2 question 3 (a and b) and experience working with different issues. This was not significant ($r = -0.05$, $p = 0.68$, $n = 63$).

NB Change is calculated by the score now - score then.

Qualitative question: When the participant has expressed a change over time in how protective / promotional they are, the factors involved in this change will include knowledge, experience of working with clients concerning particular issues and overall experience of working with this client group.

Section 2 question 2 (see Appendix 7 for verbatim responses).

Table 2 shows the reasons given for the change when participants felt they had become more protective over time when dealing with the rights of individual clients to have sexual experiences (section 2, question 2). The information was coded into five categories, ‘professional role,’ ‘greater awareness of issues,’ ‘organisational pressures,’ ‘experience of working with clients,’ and ‘other.’

Table 2: When participants became more protective concerning the rights of clients to have sexual experiences.

Category	Number of Responses	Example of response
Professional role	2	‘Nature of job leaning more towards investigating abuse.’
Greater awareness of issues	5	‘Greater awareness of the risks of harm to the client from actively promoting sexual relationships.
Organisational pressures.	2	‘Organisational pressures to avoid bad publicity / scandals.
Experience of working with Clients	2	‘Working in a forensic setting for two years with sexual offenders.’
Other	1	‘Feeling we have to understand where the power lies in a relationship.’

Table 3 shows the reasons given for the change when participants felt they had become more promoting over time when dealing with the rights of individual clients to have sexual experiences. The information was coded into four categories, ‘increased knowledge,’ ‘changes in philosophy of services,’ ‘experience of working with clients,’ and ‘other.’

Table 3: When participants became more promoting of the rights of clients to have sexual relationships.

Category	Amount of Responses	Example of Response
Increased Knowledge	7	‘Sexuality awareness training, child protection training.’
Changes in Philosophy of Service.	2	‘In a more rural location the values and attitudes towards sexual relationships differs to previous location - inner city.’
Experience of working with client.	7	‘Experience in communication with individual clients - often have more insight than other’s think.’
Changes in public opinion.	2	‘Change in education and public awareness and attitude.’
Other	2	‘Restrictive / prejudiced views of care staff.’

Section 2 question 3.

Table 4 shows the reasons given for the change when participants felt they had become more protective over time of the rights of other service users and society in cases concerning possible abusers with learning disabilities. The information was coded into three categories: ‘experience of working with abusers,’ ‘more awareness of complexities of issues surrounding abuse / consent,’ and ‘public opinion / organisational priorities.’

Table 4: When participants became more protective of other service users and society.

Category	Number of Responses	Example of Response
Experience of working with abusers.	2	‘Experience of working with abusers with learning disabilities - both have rights but safety and rights of other users are paramount.’
More awareness of issues surrounding abuse / consent.	3	‘More aware of complexities. Increased awareness of legal issues (too much experience of social services legal departments)
Public opinion / organisational priorities.	2	‘Change in climate of opinion which amounts to a ‘moral panic’ about paedophilia and other types of abuse.’

Table 5 shows the reasons given for the change when participants felt they had become more promoting over time of the rights of the referred service user in cases concerning possible abusers with learning disabilities. The information was coded into two categories: ‘experience of working with clients’ and ‘increased understanding of issues surrounding abuse.’

Table 5: When participants became more promoting of the rights of referred service users.

Category	Number of Responses	Example of Response
Experience with clients.	5	‘Came about through experience of seeing things work.’
Increased understanding of issues surrounding abuse.	5	‘Understanding of why ‘abusers’ abuse and what the term ‘abuse’ can mean.

Hypothesis 6: The more experience the participant has had in responding to sexual offenders the more protective they will be of potential victims / society.

The following correlations were performed between:

Section 1 question 6d (dealing with issues of abuse) and scenario 5a. This was not significant ($r = 0.12$, $p = 0.28$, $n = 78$).

Section 1 question 6d and scenario 5b. This showed a significant positive correlation ($r = 0.24$, $p = 0.03$, $n = 77$). This indicates that the more cases in which the participant had dealt with issues of abuse the more protective the scenario score.

Section 1 question 6e (dealing with inappropriate behaviour) and scenario 2b. This was not significant ($r = -0.13$, $p = 0.29$, $n = 74$).

4. Discussion:

4.1. Findings.

4.1.1. Demographic Details.

The participants represented a variety of professions working within community learning disability teams and many (61 per cent) had five years or more experience of working with this client group. Although the majority of the participants had received training in this area since qualifying, sixteen (21 per cent) reported that they had not received any training. It is possible though that these respondents may have been fairly new to working in this field and had not yet had the chance to take part in training. Of those that participated in training only nineteen (31 per cent) had received more than five days, most (69 per cent) receiving 1 - 5 days.

Interestingly, nearly half of the respondents had taken part in the teaching of issues concerning sexual relationships, although out of these how many had received training themselves and how much training was involved is not known.

The vast majority of participants reported that they had had experience of working with clients having a heterosexual relationship (96 per cent) and in dealing with inappropriate behaviour (95 per cent). It would have been useful to know how the inappropriate behaviour was defined. If it predominantly concerned inappropriate sexual behaviour this may have influenced how protective or promoting the individual was.

Nearly half (46 per cent) of the respondents indicated that they had had no experience of working with clients in issues concerning gay / lesbian relationships. This may be due to either low occurrence or may reflect the lack of opportunity that people with learning disabilities experience in expressing their choice of sexual relationships. It may also

reflect Cambridge's (1996) acknowledgement of the skills of the client in hiding their behaviours and their reluctance to talk with staff about what they do.

The area of work in which the highest number of participants indicated they had had no client contact, was sexually transmitted diseases including HIV. The results also indicate though that 48 per cent had at least some experience of working with these issues.

Unfortunately the questionnaire did not distinguish between HIV and other sexually transmitted diseases. It is possible therefore that cases involving HIV make up only a small percentage of the total. If this is true the inadequacies described by Thompson (1995) and Cambridge et al (1993) of service provision in this area may in part be due to staff's lack of experience of dealing with these issues.

4.1.2. Knowledge scores.

The mean knowledge score of 9.1 was fairly high as the highest possible score was 14. Only ten participants scored less than 8. The highest number of incorrect scores were for questions 11b and 11c. These questions deal with the issue of whether GPs and services for people with learning disabilities have a legal obligation to keep the HIV status of users confidential. Most participants felt that this was the case, whereas out of the three choices of answer (GPs, GUM clinics and Services for people with learning disabilities) it is only GUM clinics (11a) that have this legal obligation. This indicates that the area of confidentiality and HIV is unclear, and may also be a reflection of the fact that the majority of the participants had no experience of working with clients in this area.

4.1.3. Scenario Scores.

Scenario 2 (concerning possible abuse) had the highest number of 'protective' scores. This is to be expected as the risk factors in the scenario are clearly indicated. For example, the service user doing voluntary work has a history of suspected non-consenting

sex with other service users, and the service user he is helping has recently been showing behavioural disturbances on attendance at the day centre.

Scenario 1a (the extent to which support would be given to a heterosexual relationship) had the highest number of 'promoting' scores. This also is to be expected as any possible risk factors that might cause concern to support staff have not been included. For example the service user lives independently and receives fairly low key support, being visited by a support worker twice weekly. Her neighbour is of a similar age and ability and she has indicated that she is happy with the relationship. Despite this though there were also a small number of participants (four) who would either support their relationship only 'a little' or 'not at all.' Twenty seven participants stated that they were 'neutral.'

Another scenario which describes little in the way of risk factors is scenario 3 which involves a homosexual relationship. Seventy two per cent indicated that it would be necessary to investigate whether the individual is giving informed consent to the relationship, as opposed to 38 per cent in the case of scenario 1 concerning a heterosexual relationship. This difference in the level of assessed risk may be due to concern about HIV and AIDs. Similarly though, 60 per cent of respondents indicated that they would promote the relationship described in scenario 1 either 'a great deal' or 'quite a lot,' and only 40 per cent gave the equivalent response for scenario 3. There appear therefore, to be more concerns around the issue of a homosexual relationship than a heterosexual relationship.

Interestingly, the ratings of scenario 4 reflect perhaps the difficult role of the team in supporting the client and at the same time being aware of the needs of others. This scenario describes a couple wanting to have children. Sixty per cent of respondents indicated that they would be promoting of this choice either 'quite a lot' or 'a great deal,' and 50 per cent indicated that they would be either 'quite concerned' or 'extremely

concerned' about the welfare of the child. This is a possible example of the 'tightrope' on which professionals have to 'walk,' described by George (1997).

The fact that a wide range of responses were given to the scenarios may reflect the variation in professions represented. It is also interesting to note that on seven of the scales (representing scenario 1a, 1b, 3a, 3b, 4b, 6b, and 7a) there are ratings at each 'extreme' of the scale, representing in effect opposing views in dealing with the same issue. It is appreciated that it is difficult to make decisions based on a relatively small amount of information, but this does not explain the sometimes extremely wide diversity in the responses given.

4.1.4. Statistical Analysis.

Hypothesis 1:

It was hypothesised that the more knowledgeable the participant is the more informed will be their appraisal of risk. A significant positive correlation was found between the overall knowledge score and scenario score. This implies that the more knowledgeable the professional is the more protective is their behaviour. As only two of the scenarios (2 and 5) describe factors in which a vulnerable person is at risk of or is a possible victim of abuse, it was hoped that the overall scenario score would be a little more promoting.

Increased knowledge may mean that the individual is more aware of legal issues and feel more responsible for protecting their clients.

A significant positive correlation was also found between knowledge scores and the experience that individual's had gained in dealing with issues specifically concerning sexual relationships. This indicates that the more experience the individual has working with issues concerning sexual relationships the more knowledge they have. Team

members may therefore gain knowledge from experience in dealing with relevant issues as well as through more formal training or teaching.

No significant difference was found between the knowledge scores and different professional groups. Due to the small numbers in some of the groups though, only the three largest groups of respondents were compared, these being clinical psychologists, social workers and nurses. It would be hoped that levels of knowledge around issues of sexuality would be also be similar when comparing other professional groups within the team.

Hypothesis 2 and 3:

There was no evidence to suggest that the more experience the participant has had in responding to potential harm / health concerns the more protective they will be of clients when making decisions concerning risk. Similarly, there was no evidence to suggest that the more experience the participant has had in advocating / promoting rights the more promotional they will be of clients in sexual relationships. This indicates that previous experience of either promoting or protecting clients does not necessarily influence decisions made in the present concerning risk.

Information that has not been gathered and which might have been useful concerning risk assessment, would be outcomes of past interventions. The nature of the intervention and whether it had been judged 'successful' by the participant may influence future decisions made.

Hypothesis 4:

The results indicated that the more experience the participant had in dealing with issues concerning clients having heterosexual relationships the more promoting they were in the relevant scenario. It was also found that the more experience the participant had in

dealing with issues concerning sexually transmitted diseases including HIV the more promoting they were of the client in the scenario concerning these issues. It is interesting that experience in these instances appeared to be related to promoting sexual relationships (rather than protecting the client). Again, it would be interesting to know if previous experience of outcome in dealing with these issues had been viewed as successful by the respondent, and subsequently whether it had been a positive or negative experience for them.

There was no evidence to suggest that the type and amount of experience gained in other issues concerning sexuality related to the individual's appraisal of risk.

Hypothesis 5:

Although the mean scores (section 2 questions 2 and 3) indicate that the participants became more promotional over time of the rights of individual clients to have sexual experiences, and more promotional of the rights of possible abusers with learning disabilities, this was not to a significant degree.

It is interesting that of the forty participants who felt their level of promotion of clients having sexual relationships had changed over the years, the numbers were fairly evenly divided between those who had become more promotional (eighteen) and those who had become more protective (twenty-two). This is perhaps reflective of the variation in the scoring of the scenarios by the participants, and emphasises the very different perspectives that team members can have.

In the case of possible abusers with learning disabilities, the number of participants who felt their level of promotion of the rights of the referred service user had changed was twenty-five - a good deal less than the response to the previous question. Of these participants only eight felt they had become more promotional of the rights of the referred service user, whereas seventeen felt they had become more protective of other

service users and society. When dealing with possible abusers there is perhaps often more pressure on professionals to be protective of others first and foremost.

No significant correlation was found between the change over time in how promoting participants were of clients having sexual relationships, and both experience in years and experience of working with different issues. Similarly there was no significant correlation between the change reported in how promoting participants were of the rights of possible abusers with learning disabilities, and both experience in years and experience of working with different issues.

Respondents were asked to indicate factors that had influenced any change in how promoting / protective they were. It was hypothesised that the factors the participant would mention would include knowledge, experience of working with clients concerning particular issues and overall experience of working with this client group.

Experience of working with clients was mentioned in all four situations (more protective or promoting of clients having sexual experiences and more protective or promoting of the rights of possible abusers). Many participants stated that ‘increased awareness’ or ‘understanding’ of the issues involved had influenced their views. Unfortunately many participants did not state why they felt their awareness and understanding had improved, but it is possible that it could be related to all three factors stated in the hypothesis.

The category ‘Increased knowledge’ represented participants who mentioned taking part in formal training and / or reading articles / research in their own time. This was mainly indicated as a factor when participants had become more promoting of the rights of clients to have sexual relationships. Only one participant mentioned training as a relevant factor in the case of abusers with learning disabilities, and in that case the participant had become more promoting of the rights of the service user. This may be relevant as Thompson and Brown (1997) refer to a ‘great disparity ‘ in the understanding of the behaviour and the desired responses and treatment of men with learning

disabilities who sexually abuse. It would be useful therefore to know the extent to which staff receive training in this area.

Interestingly organisational pressures are mentioned by two participants as a factor that had influenced them in becoming more protective of clients concerning sexual experiences. The organisational pressure is described by the respondent as the avoidance of bad publicity and scandals. Similarly, organisational priorities and public opinion are factors given by two participants as reasons for becoming more protective of other service users and society, in cases concerning possible abusers with learning disabilities.

One participant describes a ‘moral panic’ regarding paedophilia and other types of abuse. This perhaps reflects the pressure felt by team members in dealing with these issues. This may also be indicated by the fact that more than twice as many staff reported becoming more protective of the rights of other service users and society, than those that had become more promoting of the rights of the referred service user in cases concerning possible abusers with learning disabilities.

Hypothesis 6:

There was no evidence to suggest that the more experience the participant has had in responding to sexual offenders the more protective they will be of potential victims / society. Accordingly perhaps, only two of the seventeen participants who became more protective of other service users and society gave experience of working with abusers as a factor in their thinking.

4.2. Questionnaire Design:

The questionnaire was designed specifically for this research, and was first used during the piloting process. Following analysis of the completed questionnaires, possible

deficiencies in the design were noted and suggestions for improvements were made as follows:

Rating scale:

The rating scale used for the scenario section ranged from 1-5 with the middle point as 3. This middle rating for each of the 14 scales was labelled as 'neutral.' Although during the piloting process no comments were made about this scale, three participants subsequently commented on the questionnaire itself that the scale was 'confusing.' An example is the scale for scenario 3a in which 1 = 'not at all,' 2 = 'a little,' 4 = 'quite a lot' and 5 = 'a great deal.' Confusion could arise as the definition of 'neutral' may be unclear.

It was hoped that using the word 'neutral' within the scale would allow participants to rate themselves as being neither 'promoting' or 'protecting' but neutral in their attitude. This perhaps, does not fit in with the scoring of the scale on a continuum. The way the scale is worded implies that 'neutral' is more than 'a little' and less than 'a lot.' In future use the wording of the scale may need to be changed. This might have implications for the scoring of this section of the questionnaire and further piloting would be needed.

Validity:

Although a reasonable level of reliability was obtained for the scenario section scores, the issue of the validity of this section of the questionnaire may require further investigation. As validity examines how well the test measures what it purports to measure (Hammond, 1995) this would mean ensuring that the questionnaire is actually measuring 'promotion' or 'protection.'

One way of doing so would be for a 'focus group' of perhaps four experts in the field of learning disability and sexuality to discuss what would constitute 'promoting' or

‘protective’ behaviour in response to each of the scenarios. Ideally these experts would represent experience of working within the different areas of sexuality such as abuse, relationships, sexual health and sexual offending.

As this was a newly devised questionnaire the study itself could be viewed as part of the extended piloting process.

4.3. Clinical Implications:

The results highlight the small amount of training that many professionals receive in issues of sexuality and people with learning disabilities. The majority of the participants indicated that they had received only 1 - 5 days training. This is perhaps reflected in the fact that the reason given most by staff who reported a change in how promoting / protective they were over the years was experience of actually working with clients. This may also be indicated by the fact that the more experience the individual has of working with sexuality issues the more knowledge they have. It appears therefore that working with clients in this area has more influence over knowledge and decision making than actual training in the specific issues involved.

It is arguable therefore whether more training is actually needed in this area although it is clear that many of the participants had gained very little experience in working with certain aspects of relationships and sexuality. The fact that there is a fairly wide variety of experience amongst respondents suggests that services may differ in the numbers of referrals they receive around certain issues. As the services were not identified within the questionnaires it is unclear as to the factors that are involved in this. It is possible though that as the region is made up of both large inner city areas and rural areas, this has some influence on the type and amount of referrals that the team receives. This may also of course be influenced to some extent by the professional background of team members, dependent also on the referral procedure of the particular team.

Training in issues of sexuality is no less important for those who have less experience in working with these issues, and may be more important as they are not perhaps gaining the opportunity to improve their skills and knowledge in the way that others with more experience have expressed within the study.

The areas in which the highest number of staff reported that they had had gained no experience of working with clients were; supporting gay / lesbian relationships (46 per cent); parents with a learning disability (31 per cent); couples / marriage (26 per cent); and sexually transmitted diseases including HIV (51 per cent). Services which have a low rate of referrals in these areas need perhaps to make sure appropriate provision is made for when referrals are made and that staff feel confident in dealing with the issues involved.

Alternately though it is perhaps promising from the point of view of the service user that a fairly large percentage of professionals did have at least some experience in working with these issues. Although there is no comparative data, the findings suggest that for many people with learning disabilities community living is providing some choice regarding relationships and sexuality (O'Brien 1987, Waitman and Reynolds, 1992). Services need to continue to be aware of these needs as they are likely to rise in the future if the aims of an 'ordinary life' (King's Fund, 1981) and the 'five accomplishments' (O'Brien, 1987) continue to be adhered to.

Some participants described 'organisational' pressures and the views of the public as reasons for changing how promotional / protective they were. It is questionable the extent to which this pressure helps the individual to make decisions, and it is important that organisations are aware of the pressures that staff can feel in dealing with issues of sexuality and how this may in turn impact on their decision making.

One respondent stated that they had moved from an inner city service to a rural service and felt that within the rural service there was a different attitude towards sexual relationships. This may have implications for service users, indicating that the type of support they receive depends upon the area in which they live. Although it is perhaps inevitable that there will be differences in attitudes within services, it is hoped that this does not mean that some clients are less likely to be supported in maintaining relationships than others.

The sometimes diverse decisions that were made concerning risk within the scenarios indicates that staff can have widely differing views in this area. This again may be due to the variety of professions that are represented as well as to the individual's own experience and value system. The diversity is also apparent in the fact that some participants felt that they had become more promoting over the years and some that they had become more protective. This emphasises the importance of working together as a team when making these decisions. Each individual can bring very different experiences and perspectives to the assessment and decision making process, leading overall to a more balanced appraisal of risk.

4.4. Future research:

The findings indicate the following areas for possible future work:

1. The comparison of teams within inner city / urban and more rural areas. Is there a difference in the number and type of referrals received concerning sexuality and people with learning disabilities? Is there a difference in how promoting / protective professionals are depending on the area in which their service is based?
2. How supported do staff feel by the organisations within which they work when dealing with issues around sexuality and people with learning disabilities, particularly in

cases of abuse and possible abusers? How does this actual / perceived support affect the risk assessment and decision making process?

3. How does the outcome of previous interventions concerning sexuality issues and people with learning disabilities influence the decision the individual makes now when assessing risk? For example if the outcomes of previous interventions working with individuals having a sexual relationship have mostly been positive, does the individual have a promotional attitude towards people with learning disabilities having sexual relationships?

4. A qualitative study looking at the factors concerning decision making and working with people with learning disabilities around issues concerning sexuality. Examining the influence of the individual's own value system may be of particular interest.

5. Due to the often extremely wide variety of responses given to the scenario questions, a larger study could explore the differences that professional background may make in the risk assessment and decision making process. Greater numbers in each professional group would be needed.

4.5. Conclusions:

The results of this study suggest that there is a wide variation amongst staff in both the amount of experience they have in dealing with issues of sexuality, and in how promoting they are of clients having sexual relationships. It was found that the more knowledge the participant had the more protective they were of the client, and the more experience of working with clients having sexual relationships, the more knowledgeable they were concerning sexuality issues.

It was also found that the more experience the participant had in working with clients having heterosexual relationships and with clients concerning sexually transmitted diseases including HIV, the more promoting they were when asked to assess the risks in a related situation. The results indicate therefore that previous experience of working within these areas, knowledge of issues concerning sexuality as well as the individual's own values, have some influence on how promoting staff are.

The move towards community living and the focus on the principles of normalisation and 'an ordinary life' mean that many people with learning disabilities should now have more choice in how they live their lives. One aspect of this choice is in forming sexual relationships. In practise though, the amount of autonomy it is possible for the individual to have in this area is questionable. It is clear that staff have a difficult role to play in both promoting the rights of the individual to have sexual relationships and at the same time 'protecting' them (and others in society) from possible abuse and exploitation.

The difficulties faced by staff are emphasised within this study by the apparent difference in the decisions often made by professionals when faced with assessing levels of risk within the same situation. When assessing the risk factors for clients therefore, the importance of teamworking and thorough knowledge based assessment that is sensitive to the rights of the individual cannot be overestimated, so that a balanced appraisal of risk can be made.

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Appendix 1:

Vanier's model outlining the negative results of society's behaviour towards people with learning disabilities.

Jean Vanier's model (Waitman and Reynolds 1992).

Rejection:

By family, by services or community facilities.

Physical Segregation:

Services that segregate the person from ordinary communities.

Isolation From Socially Valued People:

Spending most of the time in the company of other people who are also disabled and who have been rejected socially.

Lack of Roots:

Living in services dislocated from local communities, or moved between different services that reduce people retaining a sense of place or community.

Lack of Relationships:

Living with, or spending time with, other people who find it difficult to make relationships, or people they have not chosen to live with and do not particularly wish to make relationships.

Insecurity:

Living in situations of poor physical security, where they may be subject to interference from others, or where their property may be broken or stolen.

Lack of Freedom and Control:

Having things done without being consulted or even informed. Generally having little control over their lives, and having freedom severely curtailed.

Poverty:

Being materially poor, with few resources to buy, and therefore having little control over the help they need. Not being seen as a valued consumer.

Lack of Experience and Opportunity:

Being overprotected and not having key experiences of opportunities that have important aspects of development.

Attribution of Negative Characteristics by Association:

Confusions in the public mind that people with learning difficulties are also mentally ill, that people are also prone to violence.

Symbolic Markings:

The symbols and images that surround people with disabilities, such as large hospital buildings, signs saying 'handicapped children' outside a training centre (with a special school next door). Residential homes that don't look like any house that most of us would recognise.

Ill-Treatment:

The risk of physical ill-treatment, excessive use of drugs or restraint.

Awareness of Being a Burden to Others:

The experience of being spoken of by others in negative terms, or as a problem or a nuisance.

Having One's Life Wasted:

The awareness of some people that they have been denied opportunities to make a contributions to ordinary society, either through activities or relationships.

Appendix 2:

Letter to head of each learning disability service.

13th February 1998

Dear

I am a third year trainee on the South Thames Clinical Psychology Training Scheme and am currently working on my final year research dissertation. This concerns professional staff working within community learning disability teams, and how work experience and knowledge effects decisions made when working with clients who are having a sexual relationship. It will involve completing a questionnaire that includes multiple choice and scenario based questions.

The research proposal is currently being considered by the regional ethics committee, and conditional on their approval when the committee meets on March 11th, I would like to contact the community learning disability team in your area. However before approaching teams I also need your approval. I would be grateful therefore if you could contact me at the above address to let me know whether I can go ahead.

I look forward to hearing from you,

Yours sincerely,

Diane Bissmire.

Appendix 3:

Information sheet sent to participants.

Information Sheet

Diane Bissmire
c/o The South Thames Clinical Psychology Training Course
The Salomons Centre
Groombridge road
Southborough
Tunbridge Wells
KENT

Tel: 01892 515152

Dear Participant,

I am currently in my third and final year of the South Thames Clinical Psychology training scheme. For my final year research dissertation I am looking at issues of sexuality and people with learning disabilities. Specifically, I am interested in the issues that may face professional staff when working with clients who are having sexual relationships, and how previous experience of interventions and knowledge in this area may affect future decision making. All the participants will be professional members of community learning disability teams.

Enclosed is a questionnaire which requires both multiple choice and written answers. It will take approximately 20 minutes to complete. To maintain confidentiality please do not put your name or the service you work within anywhere on the questionnaire. When you have completed the questionnaire please seal it in the envelope provided. Once the data has been analysed the questionnaires will be shredded. It will not be possible to identify individual participants or the service they work within from the information provided on the questionnaire.

Once I have completed my research which will be in July, I will give written feedback of the findings to all the services that have participated in the study. If you would like any further information I can be contacted via the Salomons centre training scheme at the above address.

Thank you for your time.

Diane Bissmire.

Appendix 4:

First version of questionnaire.

Questionnaire: Staff working with people who have learning disabilities - issues concerning clients having sexual relationships.

Section 1: Experience.

Please answer the following questions:

1. What is your professional background?
2. What is your gender?
3. How many years since qualifying have you worked with people with learning disabilities?
4. Since completing your professional training have you received any further training concerning clients and issues surrounding sexual relationships?

Yes No

Estimate the number of days training you have received in dealing with sexuality issues.

5. Are you now or have you in the past been involved in the teaching of care staff / trainees / other professionals concerning clients and issues surrounding sexual relationships?

Yes No

6. Estimate the number of clients you have worked with around the following areas / issues.

a) Clients experiencing a heterosexual relationship.

None 1-5 6-10 11+

b) Supporting gay / lesbian relationship(s)

None 1-5 6-10 11+

c) Investigating consent / mutuality.

None 1-5 6-10 11+

d) Dealing with issues of abuse.

None 1-5 6-10 11+

e) Dealing with issues of inappropriate behaviour.

None 1-5 6-10 11+

f) Parents with a learning disability.

None 1-5 6-10 11+

g) Couples / Marriage.

None 1-5 6-10 11+

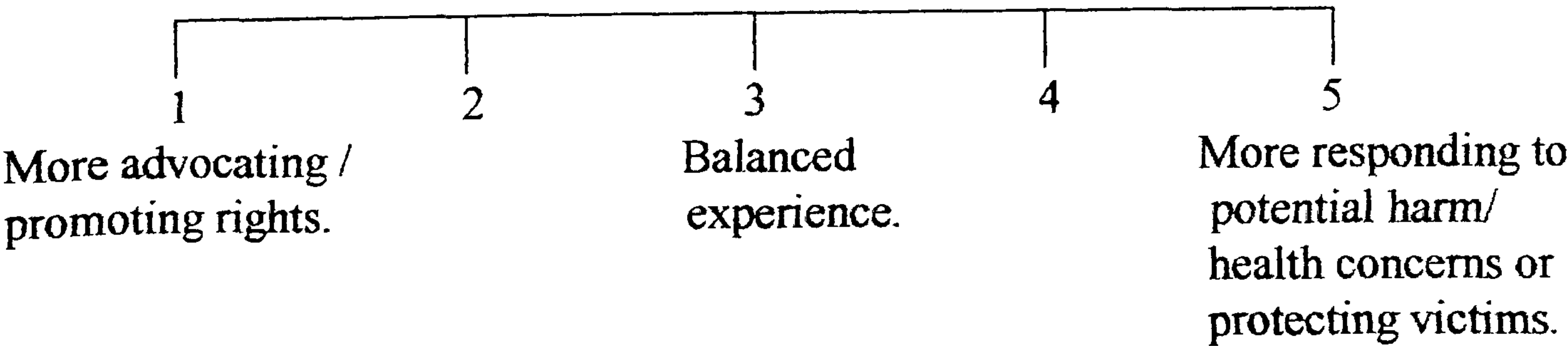
h) Sexual Health. (i) Education, preventative / Screening:

None 1-5 6-10 11+

(ii) Sexually transmitted diseases including HIV:

None 1-5 6-10 11+

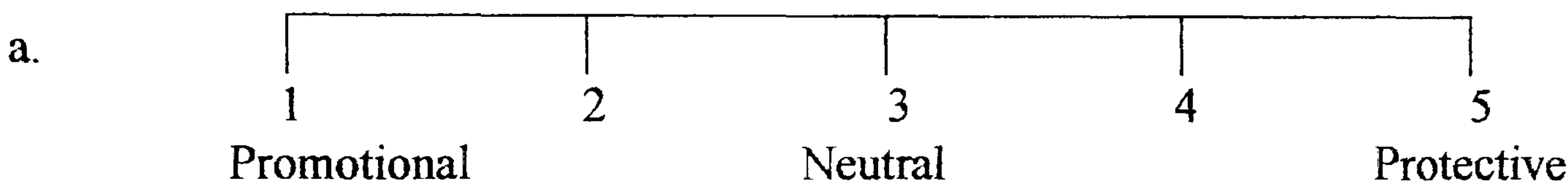
7. Overall, do you feel that your experience has been more towards advocacy/promoting the right of people with learning disabilities to sexual relationships, or investigating/responding to potential harm or illness in the person(s) concerned and/or protecting alleged victims.



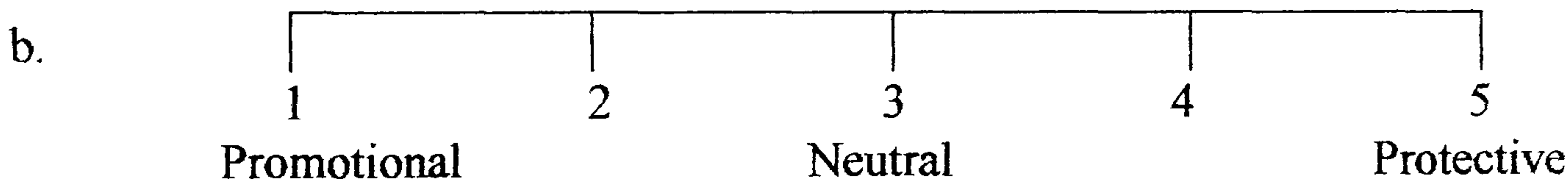
Section 2:

This section requests information as to whether you believe your response to referrals of clients with learning disabilities around sexuality issues has changed as a result of experience, training or skills acquired during your career. In particular, whether you feel that your attitudes have polarised around increased advocacy of a client’s rights or increased protection of society or the person from abuse/harm.

1. In cases where you have been involved in the rights of individual clients to have sexual experiences, at the beginning of your career how promotional / protective were you of the client? Please indicate appropriate rating where 1 is the most promotional and 5 the most cautious.

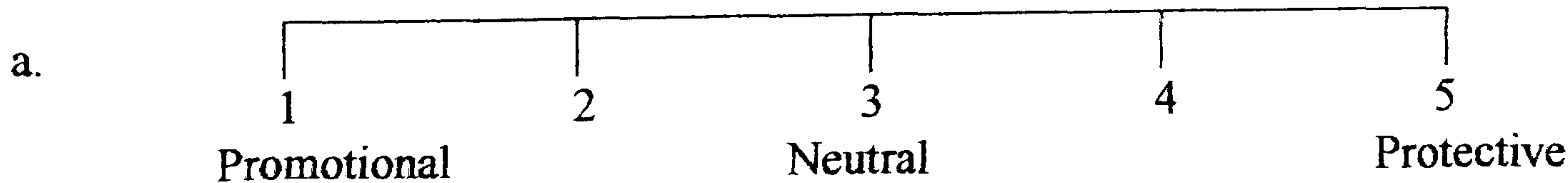


At the present time how promotional / protective are you of the client?

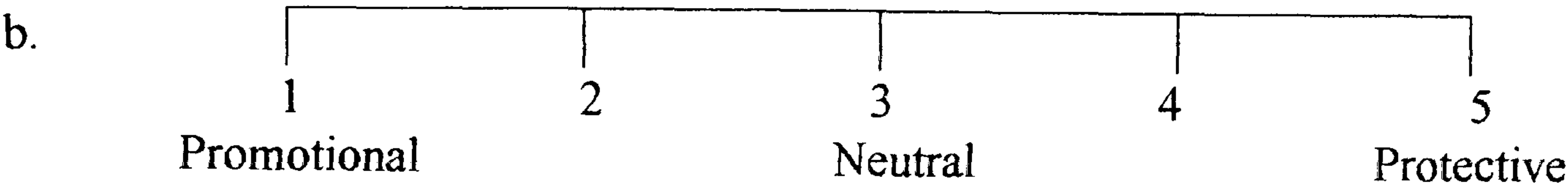


What factors do you think have led to any changes in your thinking?

2. In cases where you have been involved in issues concerning couples in sexual relationships and issues of mutuality and consent, how promotional of the relationship / protective of the couple were you at the beginning of your career?

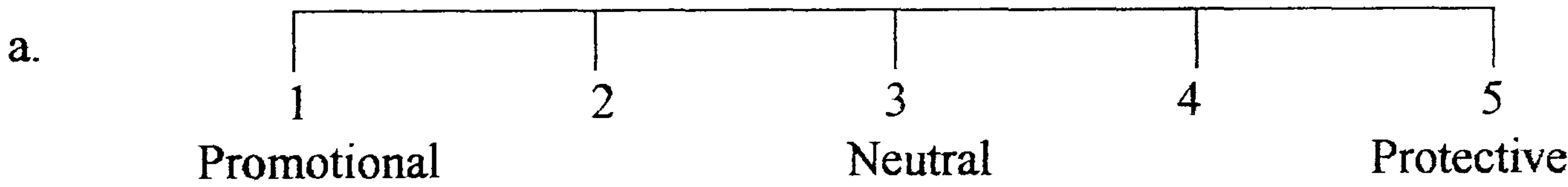


At the present time, how promotional of the relationship / protective of the couple are you?

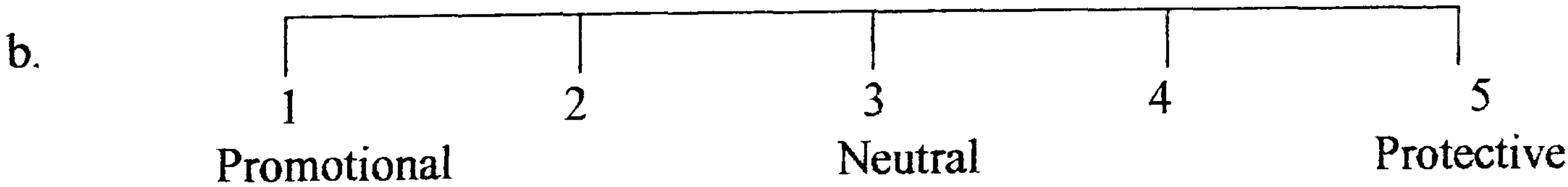


What factors do you think have led to any changes in your thinking?

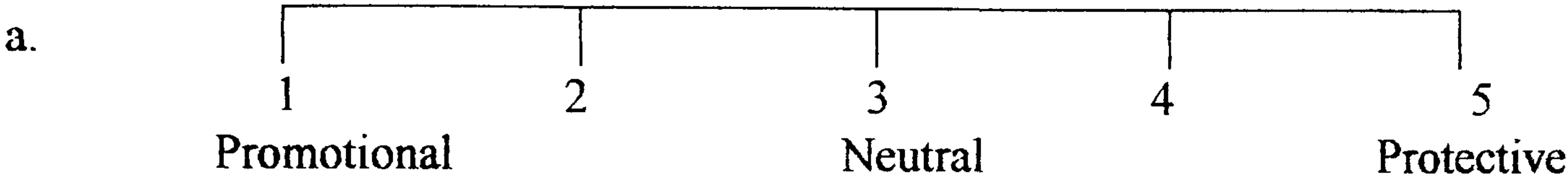
3. In cases where you have been involved in issues concerning possible abusers with learning disabilities, at the beginning of your career how promoting of the rights of the service user / protective of the rights of other service users and society were you?



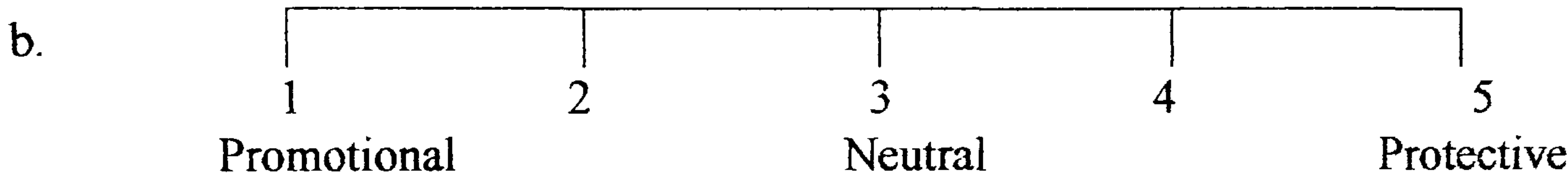
At the present time how promotional of the service user / protective of other service users and society do you think you are?



4. In cases where you have been involved in issues concerning people with learning disabilities who are possible victims of abuse, at the beginning of your career how promotional of the rights of other service users / protective of the abused client and other possible victims were you?



At the present time how promotional of the rights of other service users / protective of the abused client and other possible victims are you?



What factors do you think have led to any changes in your thinking?

Section 3: Knowledge.

Please indicate the appropriate response to the following questions:

1. People with learning disabilities are biologically more fertile.

True False

2. The children of parents who have learning disabilities are more likely to have learning disabilities than those of average parents.

True False

3. People with learning disabilities require permission by law to marry.

True False

4. Crimes committed by people with learning disabilities are more likely to be of a sexual nature.

True False

5. An abortion or sterilisation may only be performed on an adult with their consent.

True False

6. Under the Sexual Offences Act (1956) it is an offence:

a. For a man to have sexual intercourse with a woman with a severe learning disability.

True False

d. To take a woman with a severe learning disability away from a parent or guardian with intent to allow unlawful sexual intercourse with a man.

True False

7. Teaching someone to masturbate can be construed as a sexual assault.

True False

8. Male staff and managers are legally forbidden from having sexual intercourse with female clients being treated for mental disorder.

True False

9. Female staff and managers are legally forbidden from having sexual intercourse with male clients being treated for mental disorder.

True False

10. Recent changes to legislation means that the age of consent for men to engage in homosexual acts has moved from 21 years to 16 years.

True False

11. There is a legal obligation to keep the HIV status of users confidential on the part of:

a. GUM Clinics True False

b. GP's True False

c. Services for people with a learning disability True False

12. A person with a learning disability living in residential accommodation is most likely to be abused by another resident.

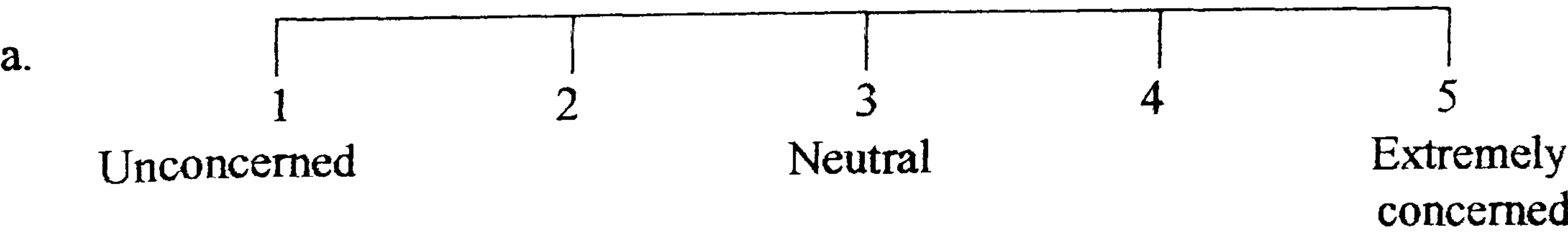
True False

Section 4: Scenarios.

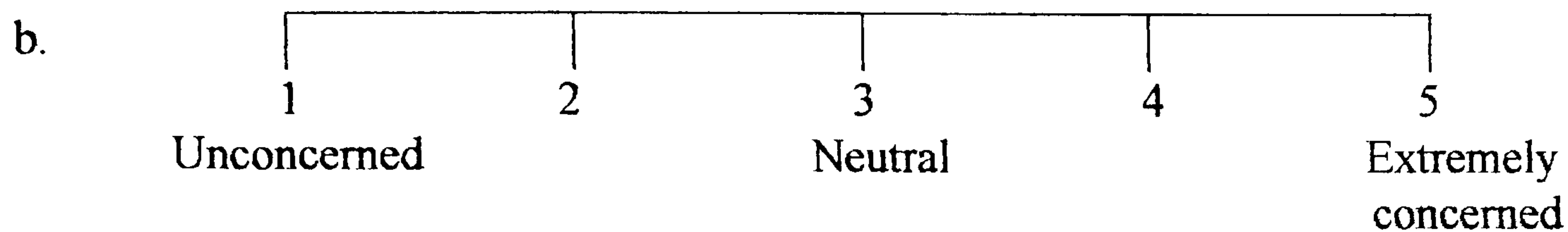
Please read the following scenarios and answer the questions following each one, rating your answer on the scale provided. It is appreciated that the information given in the scenarios is relatively brief, so could you answer as accurately as possible within these limitations.

1. Sarah lives in a flat independently and is visited on a twice-weekly basis by a community support worker. Recently she has become friends with a male neighbour of a similar age. He appears to be very supportive of Sarah and they are now spending a great deal of time together including overnight stays. As well as visiting often he has been taking Sarah out regularly and buying her gifts. Sarah tells the staff that she likes her friend but staff report she has been looking tired and upset recently.

How concerned would you be that Sarah is supported in this relationship?

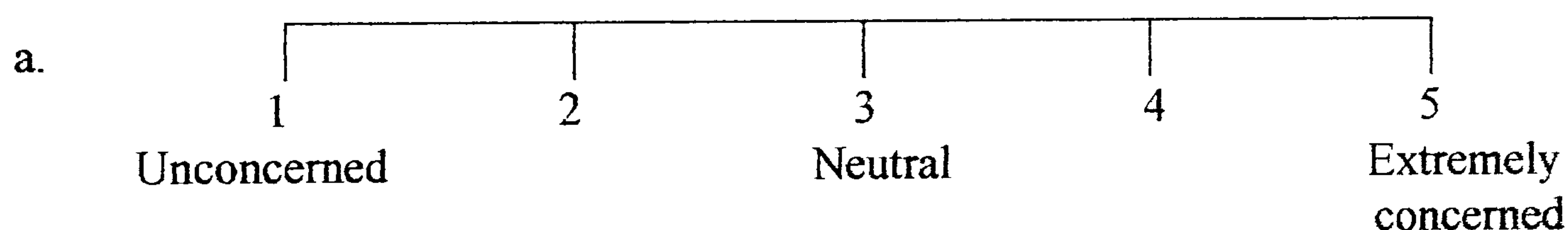


To what extent would you be concerned that issues of consent are investigated?

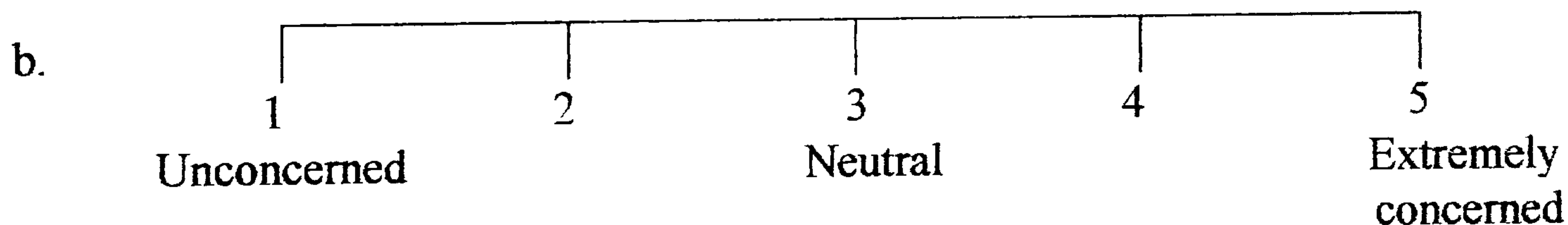


2. Chris, an able service user does voluntary work on a weekly basis at a residential unit for clients who have profound learning disabilities. There have been concerns in the past that Chris has had non-consenting sex with service users. Recently he has been spending a lot of time with Michael occasionally providing personal care. Recently Michael has become incontinent at times and now appears to be unhappy at the day centre. His self-help and personal care has deteriorated and he has shown behavioural disturbance including screaming on arrival at the day centre.

How concerned would you be that Michael may have been abused?

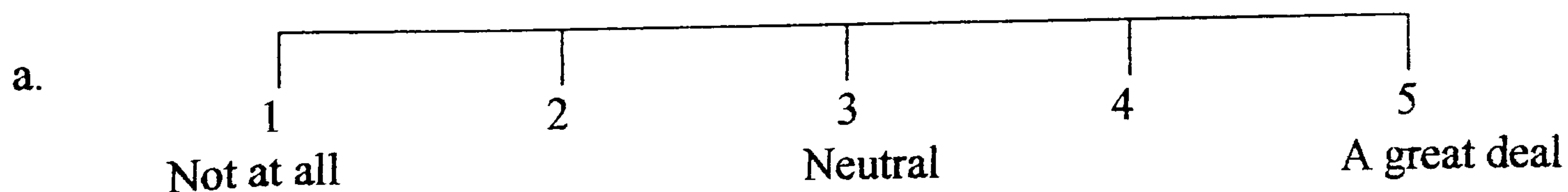


To what extent would you be happy for Chris to continue supporting Michael?

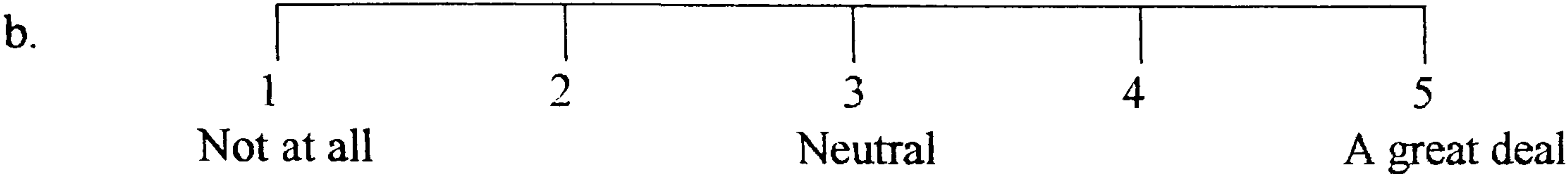


3. Mark lives in a supported hostel with three other people with learning disabilities. He has formed a friendship with Steven who he met through attending the day centre. They are spending a great deal of time together at the centre, and sometimes see each other in Steven's flat. Staff suspect that they are now having a sexual relationship.

To what extent would you want to promote Mark's relationship with Steven?

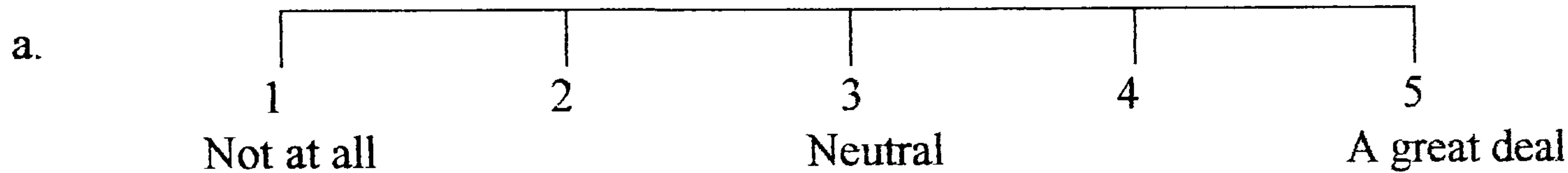


To what extent would it be necessary to investigate whether Mark is giving informed consent to the relationship?

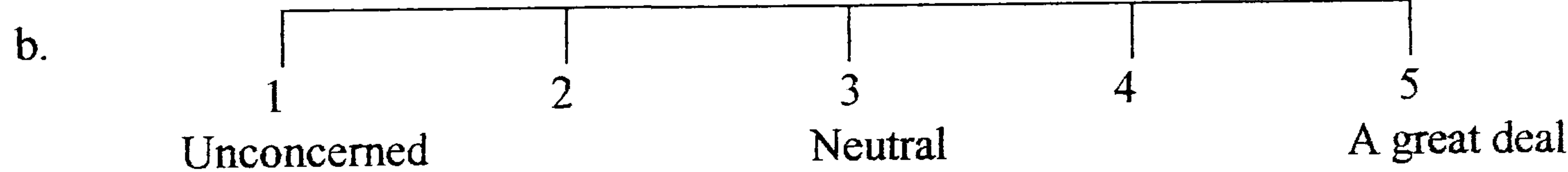


4. Peter and Lynne who both have learning disabilities have been married for six years. They live independantly and have required minimal support during this time. In a recent visit by a support worker Lynne confides that she wants to have a baby and is going to stop taking the contraceptive pill.

How promoting would you be of the rights of Peter and Lynne to have a child?

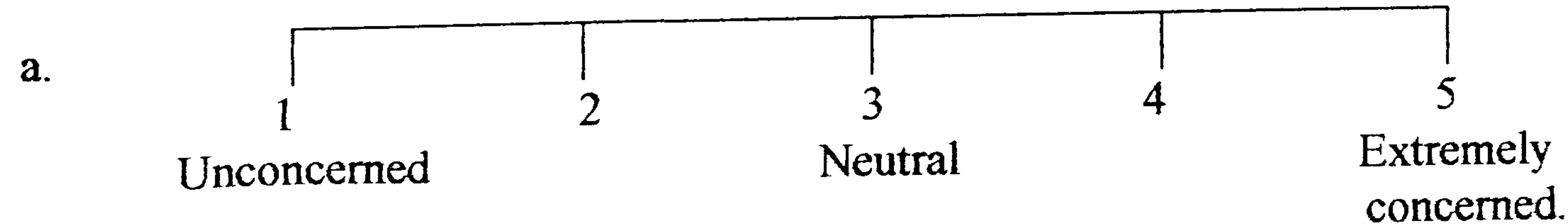


How concerned would you be for the welfare of any children that Peter and Lynne might have?

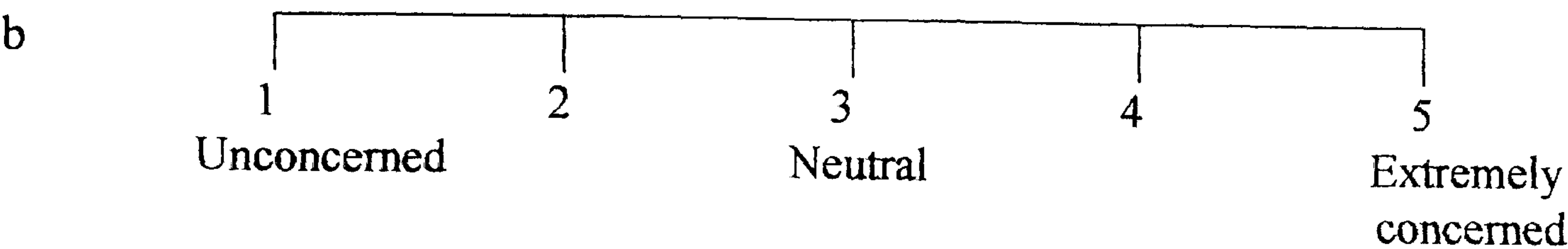


5. Mark has an interest in flying kites and spends a lot of time in the local park. Recently he has been asking staff for additional pocket money and has been buying sweets and cans of drink. Last week a staff member saw him emerge from the bushes in the park with a young boy. Both were laughing and drinking cans of coke.

How concerned would you be that Mark is lonely and seeking relationships?

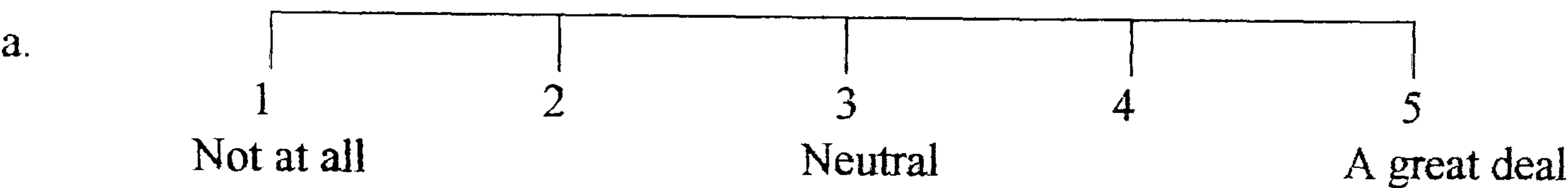


How concerned would you be that the young boy is being exploited by Mark?

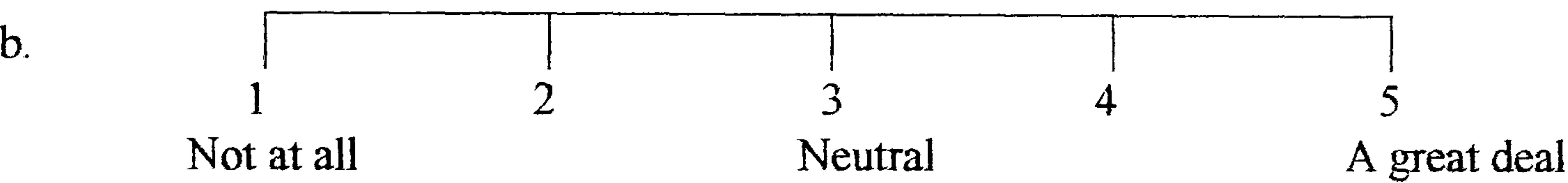


6. Susan and Mike who are both in their early 20’s, have mild learning disabilities and have going out with each other for several years. They have now informed the service that they would like to get married. Susan’s mother has stated that Mike is exploiting her daughter and that she and Susan’s father will refuse permission for the marriage to take place. The couple though are adamant that they will go ahead.

To what extent would you promote the relationship between Susan and Mike?

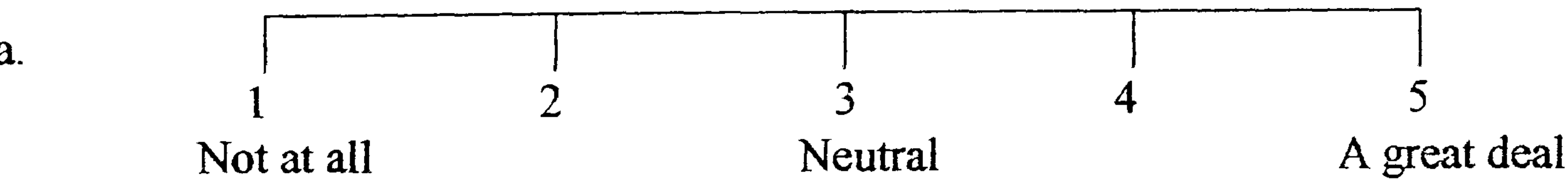


To what extent would you investigate the parents fears?

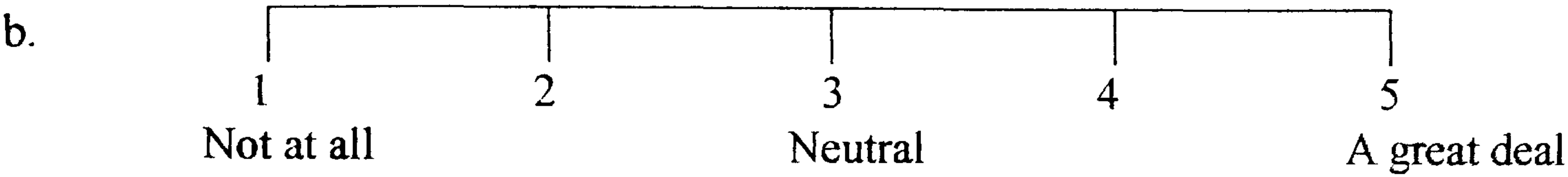


7. James has recently moved to the area and is living in a residential unit. It is known that in the past he has had many sexual partners both male and female and has been known to use intravenous drugs. He is now having a sexual relationship with Anna and has told staff not to be concerned as he ‘always’ uses condoms.

To what extent would you support James’ relationship with Anna?



How concerned would you be that Anna is at risk of contracting HIV and/or other sexually transmitted diseases?



Thank you for your time.

Appendix 5:

Answers and references for the knowledge questions.

Answers to Knowledge questions with appropriate references (section 3 of questionnaire).

Question 1 - False (Craft, 1983).

Question 2 - True. Evidence suggests that there is a greater likelihood of the children of parents with learning disabilities having learning disabilities than parents without learning disabilities, but the majority of children born to parents with learning disabilities do not have learning disabilities themselves (Hall 1974, Reed and Reed 1965, Reed and Anderson 1973).

Question 3 - False (Gunn, 1996).

Question 4 - False (Thompson and Brown, 1997).

Question 5 - True (Gunn, 1996).

Question 6a - True (Gunn, 1996) 6b - True (Gunn, 1996).

Question 7 - True (Gunn, 1996).

Question 8 - True (Gunn, 1996).

Question 9 - False (Gunn, 1996).

Question 10 - False (Gunn, 1996).

Question 11a - True (Gunn, 1996).

11b - False (Gunn, 1996).

11c - False (Gunn, 1996).

Question 12 - True (Brown and Turk, 1993).

Appendix 6:

Final version of questionnaire.

**Staff working with people who have learning disabilities.
Issues concerning clients having sexual relationships.**

Section 1: Experience.

Please answer the following questions:

1. What is your professional background?

2. What is your gender?

Male

Female

3. How many years since qualifying in your profession have you worked with people with learning disabilities?

4. Since completing your professional training have you received any further training concerning clients and issues surrounding sexual relationships and people with learning disabilities?

Yes

No

Estimate the number of days training you have received in dealing with sexuality issues for people with learning disabilities.

None

1-5

6-10

11+

5. Are you now or have you in the past been involved in the teaching of care staff / trainees / other professionals concerning clients and issues surrounding sexual relationships?

Yes

No

6. Estimate the number of clients with learning disabilities you have worked with involving the following issues. Please circle or tick your answer.

a) Clients experiencing a heterosexual relationship.

None

1-5

6-10

11+

b) Supporting gay / lesbian relationship(s)

None	1-5	6-10	11+
------	-----	------	-----

c) Investigating consent / mutuality.

None	1-5	6-10	11+
------	-----	------	-----

d) Dealing with issues of abuse.

None	1-5	6-10	11+
------	-----	------	-----

e) Dealing with issues of inappropriate behaviour.

None	1-5	6-10	11+
------	-----	------	-----

f) Parents with a learning disability.

None	1-5	6-10	11+
------	-----	------	-----

g) Couples / Marriage.

None	1-5	6-10	11+
------	-----	------	-----

h) Sexual Health:

(i) Education, preventative / Screening:

None	1-5	6-10	11+
------	-----	------	-----

(ii) Sexually transmitted diseases including HIV:

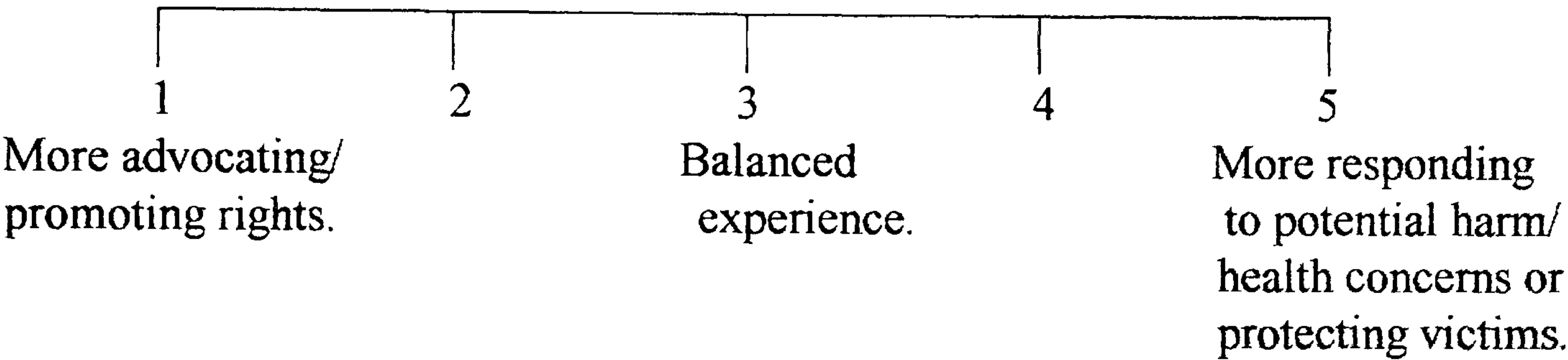
None	1-5	6-10	11+
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Section 2:

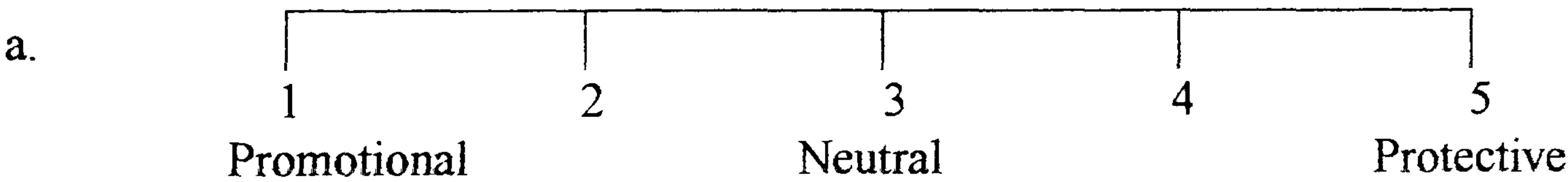
This section seeks your views on whether you think your response to referrals of clients with learning disabilities around sexuality issues has changed as a result of experience, training, or skills acquired during your career. Two possible changes (described below) are in the level of promotion of the client having a sexual relationship, and/or the level of protection of the client and/or others.

‘Promotion’ can be defined as **supporting, facilitating and enabling** a relationship to occur. ‘Protection’ can be defined as **supervising, investigating and possibly preventing** relationships and/or possible abuse/harm.

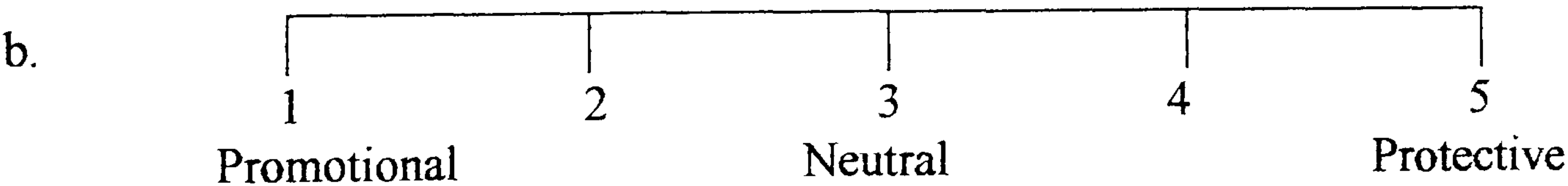
1. Overall, do you feel that your experience to date has been more towards advocacy/promoting the rights of people with learning disabilities to sexual relationships, or investigating/ responding to potential harm abuse, or illness in the person(s) concerned and/or protecting alleged victims. Please circle or tick your answer.



2. In cases where you have been involved in the rights of individual clients to have sexual experiences, at the beginning of your career how promotional / protective were you of the client? Please indicate appropriate rating **where 1 is the most promotional and 5 the most protective.**



At the present time how promotional / protective are you of the client?



What factors do you think have led to any changes (where relevant)?

3. In cases where you have been involved in issues concerning possible abusers with learning disabilities, at the beginning of your career how promoting of the rights of the referred service user or protective of the rights of other service users and society were you?

a.

1	2	3	4	5
Promotional		Neutral		Protective

At the present time how promotional of the service user or protective of other service users and society do you think you are?

b.

1	2	3	4	5
Promotional		Neutral		Protective

What factors do you think led to any changes (where relevant)?

Section 3: Knowledge.

I am interested in your specialist knowledge around sexuality issues and people with learning disabilities. Don't worry if you don't know the answers! I would appreciate however if you would attempt to answer each question.

1. People with learning disabilities are biologically more fertile.

True False

2. The children of parents who have learning disabilities are more likely to have learning disabilities than those of parents of average IQ.

True False

3. People with learning disabilities require permission by law to marry.

True False

4. Crimes committed by people with learning disabilities are more likely to be of a sexual nature.

True False

5. An abortion or sterilisation may only be performed on an adult with their consent.

True False

6. Under the Sexual Offences Act (1956) it is an offence:

a. For a man to have sexual intercourse with a woman with a severe learning disability.

True False

b. To take a woman with a severe learning disability away from a parent or guardian with intent to allow unlawful sexual intercourse with a man.

True False

7. Teaching someone to masturbate can be construed as a sexual assault.

True False

8. Male staff and managers are legally forbidden from having sexual intercourse with female clients being treated for mental disorder.

True False

9. Female staff and managers are legally forbidden from having sexual intercourse with male clients being treated for mental disorder.

True False

10. Recent changes to legislation means that the age of consent for men to engage in homosexual acts has moved from 21 years to 16 years.

True False

11. There is a legal obligation to keep the HIV status of users confidential on the part of:
- | | | |
|---|------|-------|
| a. GUM Clinics | True | False |
| b. GP's | True | False |
| c. Services for people with a learning disability | True | False |

12. A person with a learning disability living in residential accommodation is most likely to be abused by another resident.

True False

Section 4: Scenarios.

Please read the following scenarios and answer the questions following each one, rating your answer on the scale provided. It is appreciated that the information given in the scenarios is relatively brief, so could you answer the questions based on your initial impressions. Please circle or tick your answer.

1. Sarah lives in a flat independently and is visited on a twice-weekly basis by a community support worker. Recently she has become friends with a male neighbour - Tony - of a similar age and ability. He appears to be very supportive of Sarah and they are now spending a great deal of time together including overnight stays. As well as visiting often they have been going out regularly and buying each other gifts. Sarah tells the staff that she likes her friend.

To what extent would you want to promote Sarah's relationship with Tony?

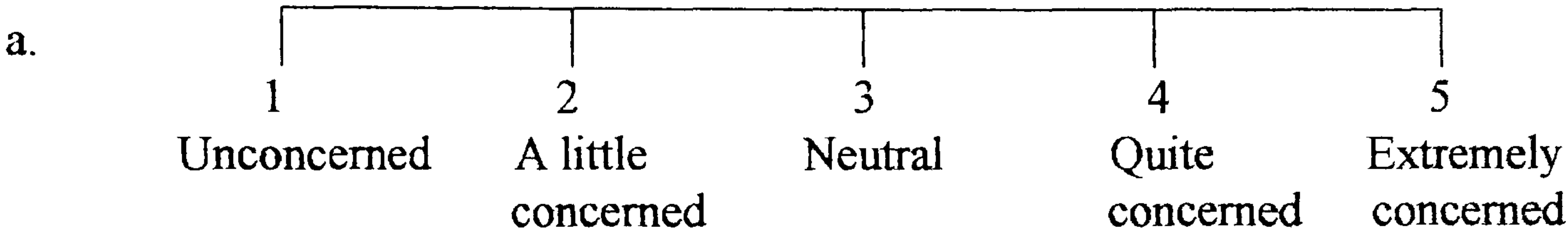
- a.
- | | | | | |
|--------------|-------------|---------|----------|------------|
| 1 | 2 | 3 | 4 | 5 |
| A great deal | Quite a lot | Neutral | A little | Not at all |

To what extent would you be concerned that issues of consent are investigated?

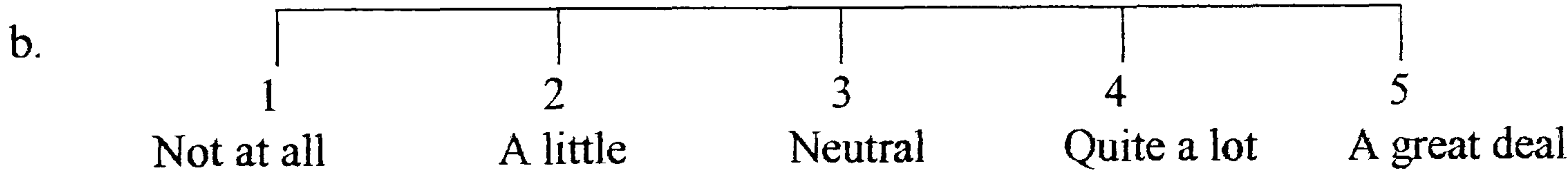
- b.
- | | | | | |
|-------------|------------------|---------|-----------------|---------------------|
| 1 | 2 | 3 | 4 | 5 |
| Unconcerned | Mildly concerned | Neutral | Quite concerned | Extremely concerned |

2. Chris, an able service user does voluntary work on a weekly basis at a residential unit for clients who have profound learning disabilities. There have been concerns in the past that Chris has had non-consenting sex with service users. Recently he has been spending a lot of time with Michael occasionally providing personal, care. Recently Michael has become incontinent at times and now appears to be unhappy at the day centre. His self-help and personal care has deteriorated and he has shown behavioural disturbance including screaming on arrival at the day centre.

How concerned would you be that Michael may have been abused?

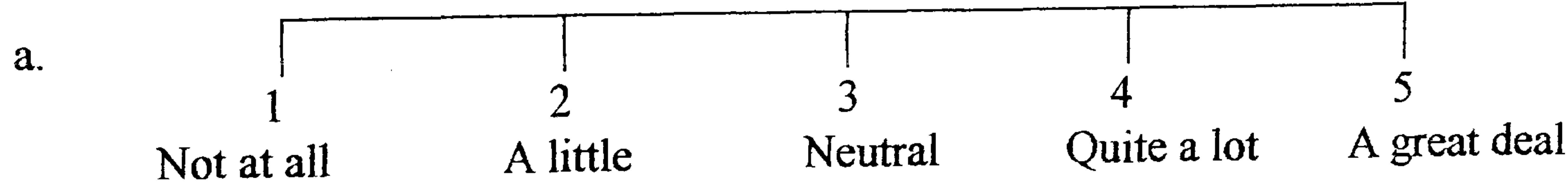


To what extent would you be happy for Chris to continue supporting Michael?

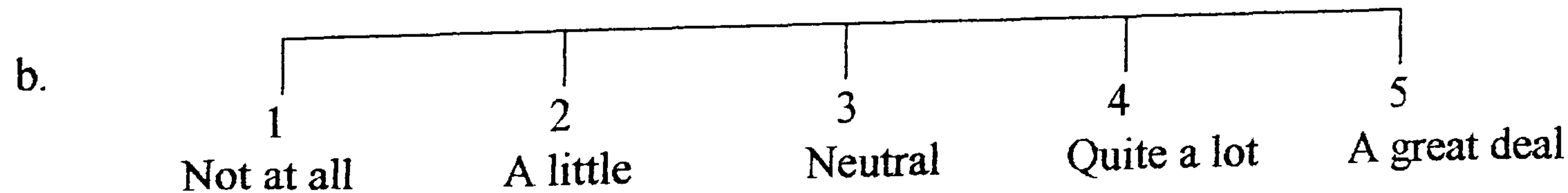


3. Leon lives in a supported hostel with three other people with learning disabilities. He has formed a friendship with Steven who he met through attending the day centre. They are spending a great deal of time together at the centre, and sometimes see each other in Steven's flat. Staff suspect that they are now having a sexual relationship.

To what extent would you want to promote Leon's relationship with Steven?



To what extent would it be necessary to investigate whether Leon is giving informed consent to the relationship?



4. Bikash and Lynne both have learning disabilities and have been married for six years. They live independently and have required minimal support during this time. In a recent visit by a support worker Lynne confides that she wants to have a baby and is going to stop taking the contraceptive pill.

How promoting would you be of the rights of Bikash and Lynne to have a child?

- a.
- | 1 | 2 | 3 | 4 | 5 |
|------------|----------|---------|-------------|--------------|
| Not at all | A little | Neutral | Quite a lot | A great deal |

How concerned would you be for the welfare of any children that Bikash and Lynne might have?

- b.
- | 1 | 2 | 3 | 4 | 5 |
|-------------|--------------------|---------|-----------------|---------------------|
| Unconcerned | A little concerned | Neutral | Quite concerned | Extremely concerned |

5. Mark has an interest in flying kites and spends a lot of time in the local park. Recently he has been asking staff for additional pocket money and has been buying sweets and cans of drink. Last week a staff member saw him emerge from the bushes in the park with a young boy. Both were laughing and drinking cans of coke.

How concerned would you be that Mark is lonely and seeking inappropriate relationships?

- a.
- | 1 | 2 | 3 | 4 | 5 |
|-------------|--------------------|---------|-----------------|---------------------|
| Unconcerned | A little concerned | Neutral | Quite concerned | Extremely concerned |

How concerned would you be that the young boy is being exploited by Mark?

- b.
- | 1 | 2 | 3 | 4 | 5 |
|-------------|--------------------|---------|-----------------|---------------------|
| Unconcerned | A little concerned | Neutral | Quite concerned | Extremely concerned |

6. Susan and Mike who are both in their early 20’s, have mild learning disabilities and have going out with each other for several years. They have now informed the service that they would like to get married. Susan’s mother has stated that Mike is exploiting her daughter and that she and Susan’s father will refuse permission for the marriage to take place. The couple though are adamant that they will go ahead.

To what extent would you promote the relationship between Susan and Mike?

a.

1	2	3	4	5
Not at all	A little	Neutral	Quite a lot	A great deal

To what extent would you investigate the parents fears?

b.

1	2	3	4	5
Not at all	A little	Neutral	Quite a lot	A great deal

7. James has recently moved to the area and is living in a residential unit. It is known that in the past he has had many sexual partners both male and female and has been known to use intravenous drugs. He is now having a sexual relationship with Anna, another service user and has told staff not to be concerned as he ‘always’ uses condoms.

To what extent would you support James’ relationship with Anna?

a.

1	2	3	4	5
Not at all	A little	Neutral	Quite a lot	A great deal

How concerned would you be that Anna is giving informed consent to the relationship?

b.

1	2	3	4	5
Unconcerned	A little concerned	Neutral	Quite concerned	Extremely concerned

Please feel free to add any comments overleaf.
Thank you for your time in completing this questionnaire.

Additional Comments:

Appendix 7:

Qualitative data - verbatim.

Qualitative data.

Section 2 question 2b

When response was 'more protective.'

- Changing role of the psychologist in the service. Sheer weight of referrals involving abuse.
- Nature of job leaning more towards investigating abuse. Promotional work usually done by nurses. (Social Worker)
- Now more aware of difficulties and health difficulties. Involved in self-advocacy and difficult relationships. Promotional role but more aware of protection issues.
- Legal framework making promotional approaches 'risky.' Organisational pressures to avoid bad publicity/scandals. The complexities of 'consent.'
- Multi-disciplinary discussion/debate has made me more aware that there needs to be a balance between promotion and protection.
- Greater awareness of the risks of harm to the client from actively promoting sexual relationships. Experience of working with situations where it is impossible to really establish whether a client is consenting or not.
- Greater understanding of clients vulnerability to influence by professionals.
- Consideration of potential for exploitation/abuse.
- More awareness of abuse, difficulties of ensuring real consent/mutuality, lack of back up from management when advocating rights, particularly when these conflict with parent or carers wishes and views.
- Working in a forensic setting for two years with sexual offenders.
- Caution around issues of consent. Feeling we have to understand where the power lies in a relationship - if with an individual who is liable to abuse that power. Could be concerned with my accountability and a belief I need to check issues above thoroughly every time. Not always a situation I'm happy with - too protective.

When response was 'more promoting.'

- Societies views, training, research, confidence.
- Developing confidence in working with new client group and increasing knowledge about clients with a learning disability.
- Sexuality awareness training, child protection training. Better understanding of clients needs and confidence to promote.
- Realisation that given proper education and advice most people with learning disabilities can develop healthy sexual relationships, their need is no less than the rest of the population - have a right to have needs met.
- Increased knowledge through studying, greater awareness of people's rights, networking better with other agencies.

- I changed jobs. In a more rural location the values and attitudes towards sexual relationships differs to previous location - inner city.
- When both clients really want the relationship and it seems fairly balanced.
- Changes in philosophy. Change from working in 'institutions' with 3,000 plus.
- Restrictions which are placed on people - no privacy, treated like children.
- Change in education and public awareness and attitude.
- Clinical experience, training, reading on subject.
- Experience. Team - led discussion.
- Experience of working with people and listening to their views.
- Clients rights.
- Experience as a practitioner over the years. Risk assessment and guidelines procedures. Advocacy awareness.
- Restrictive / prejudiced views of care staff.
- Training, experience, knowledge of those involved.
- Training, experience, listening to informed choices of individuals.
- Experience and knowledge.
- Awareness of philosophies of services and colleagues and confidence increased to work in area, awareness of 'successful couples' who have learning disabilities.
- Experience in communication with individual clients (often have more insight than other's think). Having attended post graduate courses on issues of sexuality and abuse in relation to people with learning disabilities and the general population. By giving information in a way that is specific and easily understood by the person. I am both promotional and protective by aim to clarify the understanding of the client whilst in general promoting their rights.

Section 2 question 3.

When response was 'more protective.'

- An understanding of the wider picture.
- Experience of working with abusers with learning disabilities - both have rights but safety and rights of other users are paramount, but acknowledging the cycles of abuse and insight into abusers behaviour.
- Several referrals involved young men with learning disabilities abusing or seeking sexual relationships with more vulnerable service users - the priority from referrers or organisations was usually to protect others.
- Increased awareness of the complexities of consent and sexual / romantic relationships.
- More experience = less certainty. More aware of complexities. Increased awareness of legal issues (too much experience of social services legal departments). Increasingly confident in professional opinions.
- Change in climate of opinion which amounts to a 'moral panic' about paedophilia and other types of abuse. Greater awareness of prevalence of abuse. Growing scepticism about availability of effective interventions to stop abusers reoffending.

When response was ‘more promoting.’

- Came about through experience, seeing things work. Provided an understanding of factors associated with offending is developed and services provide appropriate supports and adequate safeguards, it is possible for individuals to have a reasonable quality of life without compromising the rights of service users.

- The law, publicity, advocacy, choice and decision making, communication aids.

- Some potential abusers may abuse because needs are not being addressed adequately. If needs addressed perhaps would not find themselves in abusing relationships.

- Understanding of why ‘abusers’ abuse and what the term ‘abuse’ can mean.

- Change in attitude and awareness.

- Experience.

- Various nursing articles. Career experience and maturity.

- More aware of there being two sides to each story.

- Training, experience, knowledge of those involved.

- Consideration of needs of client.